Suffolk County Council Autism all age assessment 2022 – data section

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Contents

Executive summary2
Definitions3
Prevalence of ASD
Estimated prevalence of ASD in Suffolk residents4
Recorded figures for ASD in Suffolk populations5
NHS data5
School census data on ASD in children and young people6
Prevalence in Suffolk6
Distribution of pupils by type of school7
Ethnicity9
Deprivation10
Data from Suffolk's Children's and Young People's Services11
Autism in Suffolk adults12
Suffolk County Council data
Personal Independence Payments14
Trends in diagnosis15
Impact of delayed diagnosis, or diagnosis in later life17
Projections of population with autism17
Inequalities
Education
Social inequalities
Economic inequalities
Employment20
Access to health care20
Criminal justice system21
Impact of COVID-1921
Autism and health22
Mortality22
Other neurodevelopmental and learning disabilities

Mental health conditions	23
Wellbeing	24
Physical health conditions	24
Health checks and screening	25
NHS and adult social care service use	26
Table 14: Weekly costs by customer need, SCC ACS, March 2023	26
Figure 16: Service use by ACS customers with autism compared to all ACS customers, March 2023	27
Table 15: SCC ACS customers by employment status, March 2023	27
Figure 18: Count of SCC ACS customers with autism by Connect area, March 2023	29
Carer support	29
Assuring transformation	30
Safeguarding data for people aged 18-64 years	30
References	32

Executive summary

- People with Autism Spectrum Disorder (ASD) have different support needs, and not everyone with ASD will have a diagnosis (Definitions)
- Over 2,000 school age children in Suffolk had Autism Spectrum Disorder (ASD) as their primary Special Educational Need (SEN) support reason in 2021/22
- Around 5,160 people (3,110 8,550) aged 16 or over in Suffolk, in 2022, are estimated to have ASD, based on the latest national prevalence rates (Estimated prevalence of ASD in Suffolk residents)
- Around 40% of people with ASD will have a Learning Disability (LD), and around 30.7% of people with a LD will have ASD (NHS data, Other neurodevelopmental and learning disabilities)
- Prevalence does not appear to change significantly by age, suggesting any apparent increase in the number of children being diagnosed is due to improved identification rather than new causes
- Females may be more likely to "mask" or be mislabelled with a mental illness
- Rates of referrals for suspected autism increased significantly in the sub-ICB (Integrated Care Board) areas that cover Suffolk between 2020/21 and 2021/22. This may be affected by the COVID-19 lockdowns.
- Autistic people are almost 16 times more likely to have a long-term health condition than people without autism. 70% of autistic people are estimated to have a mental health condition
- Autistic people often experience health, social and economic inequalities

Definitions

Feedback from development of the All age autism strategy for Suffolk is that there is no single way to describe autism and autistic people that is universally accepted. The people (including autistic people) involved in developing the strategy have recommended using:

- Lower case "a", as autism is not a proper noun, and using a capital letter may make the word look intimidating or too negative.
- autism and autistic
- autistic person and people
- autistic children, young people and adults
- Which terms should be used to describe autism? Perspectives from the UK autism community)

Many terms are based on medical, rather than social models, including Autistic Spectrum Disorder (ASD) and Asperger's syndrome. Much of the data used in this report is from national sources (including NHS) and uses the terms from those resources to be consistent and for clarity. This means that different terms will be used throughout this report that are not our locally preferred words.

Autism is a neurodevelopmental condition:

Autism is a lifelong condition. It affects how a person communicates with, and relates to, other people and how they experience the world around them. A person will usually have had persistent difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests since early childhood, to the extent that these limit and impair everyday functioning.¹

It is a "spectrum condition", meaning different people will be affected in different ways, and require different levels of support². Asperger's syndrome is a form of autism³.

Pervasive developmental disorder (PDD) is a term that is sometimes used to encompass autism, Asperger's syndrome and atypical autism (or PDD-NOS [not otherwise specified]).⁴

Autism is not a learning disability,⁵ however, around 40% of autistic people have a learning disability⁶.

The IPC emphasise⁷, referencing The National Autistic Society:

"Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence."

Prevalence of autism

In 2016, NHS Digital published revised prevalence figures for autism (referred to in the report as Autism spectrum disorders (ASDs)), combining data from the 2007 and 2014 surveys (Table 1). The combined prevalence shows that autism is significantly higher in men aged 16 and over (1.5%, 95% confidence intervals (CI) 0.8% - 2.6%) than women (0.2%, 0.1%-0.6%).

	16-34	35-54	55-74	75+	All
Men	2.6%	0.2%	2.0%	0.7%	1.5%
CI lower limit	1.1%	0.1%	0.9%	0.2%	0.8%
CI upper limit	6.1%	0.7%	4.5%	3.3%	2.6%
Women	0.6%	0.0%	-	-	0.2%
CI lower limit	0.2%	0.0%	-	-	0.1%
CI upper limit	1.9%	0.3%	-	-	0.6%
All adults	1.6%	0.1%	1.0%	0.4%	0.8%
CI lower limit	0.8%	0.0%	0.4%	0.1%	0.5%
CI upper limit	3.3%	0.4%	2.1%	1.7%	1.3%

Table 1: Prevalence of autism (2007 and 2014 combined) in England, by age and sex⁸

Prevalence does not appear to change significantly by age, suggesting any apparent increase in the number of children being diagnosed is due to improved identification rather than new causes⁹.

Females may be more likely to "mask" ("pretending to be normal and fitting in") or to be mislabelled with a mental illness. Women diagnosed with autism in adulthood may be more likely than men to have previously been misdiagnosed with personality disorders or other conditions ¹⁰.

Adults with learning disabilities are more likely to have autism, compared to the population as a whole^{11,12}.

Estimated prevalence of autism in Suffolk residents

2016 (Table 1) figures have been used to estimate current (2022) prevalence in Suffolk (Table 2): around 5,160 people (3,110 - 8,550) aged 16 or over.

This is lower than The Institute of Public Care (IPC)'s estimate that 6,019 people aged 18 or over had autism in Suffolk in 2020. Their projections, from Projecting Adult Needs and Service Information (PANSI)⁷ and Projecting Older People Population Information System (POPPI)¹³, use out of date prevalence rates (1.0%, 2007 Adult Psychiatric Morbidity Survey (APMS)¹⁴ but are included as Table 12 in this report as they are widely used.

	16-34	35-54	55-74	75+	All
Suffolk men total population	79,728	91,387	98,168	42,609	311,892
Men with autism (estimate)	2,085	195	1,975	315	4,565
CI lower limit	885	55	870	70	2,600
Cl upper limit	4,825	675	4,415	1,395	7,975
Suffolk women total population	74,236	93,577	103,396	52,288	323,497
Women with autism (estimate)	465	40	-	-	660
CI lower limit	150	5	-	-	240
Cl upper limit	1,405	285	-	-	1,820
Suffolk adult total population	153,972	184,968	201,563	94,897	635,400
All adults with autism (estimate)	2,475	225	1,930	360	5,160
CI lower limit	1,205	75	855	80	3,110
Cl upper limit	5,050	665	4,320	1,565	8,550

Table 2: Estimates of autism prevalence in Suffolk, based on 2016 figures, using ONS population projections for 2022

Estimates rounded to 5. Numbers for men and women will not sum to "all adults" as difference prevalence rates have been used (Table 2).

The rate in men was higher than women (Table 1), which fits with the profile found in childhood population studies, and with reviews of global prevalence of autism (median male-to-female ratio of 4.2)¹⁵.

The estimated prevalence for pervasive development disorder (PDD) / autism spectrum disorder (ASD) was 1.2% for 5 to 19 year olds in 2017 (England, 0.9-1.4% 95% Confidence Intervals), with a higher rate (1.9%, 1.5-2.4%) for boys than girls (0.4%, 0.2-0.6%) (Table 3).¹⁶

Table 3: Prevalence of pervasive development disorder/ autism spectrum disorder in England, 5 - 19 year olds, 2017, by sex¹⁶

	Rate (%)	Lower Confidence Interval (95%)	Upper Confidence Interval
All	1.2%	0.9%	1.4%
Male	1.9%	1.5%	2.4%
Female	0.4%	0.2%	0.6%

Table 4: Estimated PDD/ASD prevalence in Suffolk, based on data from the Mental Health of Children and Young People in England 2017, using ONS population projections for 2022¹⁶

	Estimated number	Lower Confidence Interval	Upper Confidence Interval
All	1,565	1,175	1,825
Male	1,275	980	1,595
Female	260	135	390

Estimates rounded to 5. Numbers for men and women will not sum to "all adults" as difference prevalence rates have been used (see Table 3).

Recorded figures for autism in Suffolk populations

NHS data

Experimental statistics are collected on the Health and Care of People with Learning Disabilities and people with autism¹⁷. These data are not complete, for example, collection has been impacted by COVID-19, and no data was collected from SystmOne (TPP) in 2021/22, meaning that no figures were recorded for the Ipswich and East Suffolk sub-ICB area, so the figures for 2020-21 have been used in (Table 5).

Table 5: Recorded numbers of patients with autism (incomplete), 2020-21, sub-ICB areas covering Suffolk

		Patients recorded on their general	
	Patients with	practice's QOF learning disabilities	
	an autism	register who have a diagnosis of	
	diagnosis	autism, as at the end of the reporting	Patient
	(LDOB078)	period (LDOB077)	coverage
Ipswich & East Suffolk (06L)	112	21	4.0%
West Suffolk (07K)	472	72	25.1%
Norfolk & Waveney (26A)	1,027	201	15.9%

In 2021-22, 0.9% patients in England had a record of autism (without a learning disability) and 30.7% of patients in England who had a recorded learning disability (LD) also had a diagnosis of autism¹². This might suggest (using April 2021 patient numbers¹⁸) over 6,000 autistic patients (without LD) and over a thousand patients with LD and autism in Suffolk (Table 6, figures rounded to nearest 5).

Table 6: Estimated prevalence of autism (with and without LD) by sub-ICB area, Suffolk, 2021-22

	2021-22 QOF LD register	Estimated LD and autism	Total patient list (April 2021)	Estimated autism only prevalence
Prevalence (England)		30.7%		0.9%
lpswich & East Suffolk (06L)	2,268	695	415,872	3,745
West Suffolk (07K)	1,302	400	259,222	2,335
Norfolk & Waveney (26A)	7,628	2,340	1,073,983	9,665

School census data on autism in children and young people

Prevalence in Suffolk

NICE reports:

"There are about 3–4 times more boys affected by ASD than girls, although this varies across the spectrum... however, there is anecdotal evidence that ASD may be under-recognized in girls without a learning (intellectual) disability."¹⁹

2,086 school age children in Suffolk had an Autistic Spectrum Disorder (ASD) as their primary Special Educational Need (SEN) support reason in 2021/22. 1,636 (3.1%) male pupils in Suffolk (from under 2 to over 19) had ASD as primary SEN (statistically similar to England 3.3%) and 450 female pupils (0.9%, slightly, but significantly, lower than England 1.0%)²⁰. This gives a prevalence in the population included in the school census of 2.0% in Suffolk (and the East of England), significantly lower than England (2.2%). These prevalence figures are significantly higher than the national prevalence estimate (1.2%, Table 3) for "pervasive development disorder / ASD" in 5 to 19 year olds from 2017. Note that the school census has limited data on children aged 0-4 and 16-19.

The data on children with ASD in Suffolk in Figure 1 and Figure 2 came from Office for Health Improvement and Disparities (OHID) analysis for Fingertips of the Department for Education school census²¹, so it should include all school-age children (aged 4-16): some, but not all, autistic individuals aged 0-4 or 16-19 will be captured in this data. For example, a comparison of school census figures for 2020/21 with Census data showed difference of 3.0% or less for ages 4-15, but the school census had under half the expected number of 16 and 17 year olds. The school census figures for SEN do not include children at colleges (where many pupils go for post-16 education) or at feepaying schools, Suffolk children attending schools outside the county, nor home-schooled children. There was some evidence during the pandemic that the numbers of home-schooled children with autism or other SEN increased²². In March 2023, 93 pupils in Suffolk were recorded with a placement of Elective Home Education, of which 35 (37.6%) had a record of ASD.

It is known that a number of children with ASD also have learning disabilities (LD), and that correctly categorising the primary need for each individual can be particularly difficult, potentially causing available data to not be a true and accurate reflection of the actual status of ASD and LD. In 2021/22, 505 Suffolk pupils were recorded with a secondary need of ASD. The most common primary needs (for pupils with a secondary SEN ASD) were: Severe learning disability (180 pupils), and Speech, Language and Communications needs (118 pupils).

The number of pupils recorded as having ASD has been increasing in Suffolk over recent years, in line with the national trend for England.

To provide wider context around the population of children and young people recorded with ASD in Suffolk, rates were compared with national (England) levels. The Suffolk rate (18.1 per 1,000) was statistically similar to England (18.0 per 1,000) in 2020 (Figure 1).

Figure 1: Children with primary special education need of ASD, crude rate per 1,000 pupils, Suffolk compared to England, 2015-2020 21



Suffolk consistently had statistically significantly higher rates of children with ASD that are known to schools between 2015 and 2020 when compared with the average of those of Statistical Nearest Neighbours (SNNs) (Figure 2). Suffolk's SNNs for children's services are (in descending order of "closeness"): Somerset, Norfolk, Devon, Cornwall, Dorset, Shropshire, Lincolnshire, East Sussex, Worcestershire, Gloucestershire.

Figure 2: Children with primary special education need of ASD, crude rate per 1,000 pupils, Suffolk compared to SNNs, 2015-2020²¹



Rates for ASD as a primary SEN have been increasing since 2015/16, following the national trend (Figure 1).

Distribution of pupils by type of school

Total rates for Suffolk track the rates for Suffolk state-funded primary and secondary schools, where most pupils with primary SEN of ASD are taught. Fewer children with ASD are schooled in other types of education (Table 7), but rates per 100,000 for children with ASD in pupil referral units and special schools are significantly higher (Figure 3).

In 2021/22, 85.6% of Suffolk students (1,786/2,086) with a primary SEN of ASD were educated in mainstream schools. 13.6% (284/2086) in special schools, and less than 1% (0.8%, 16) in pupil referral units.

Table 7: Rate of Suffolk pupils with primary special educational need ASD recorded by setting, per 100,000 pupils, ages from "under 2" to "over 19", 2021-22

School type	England rate per 100,000	East of England rate per 100,000	Suffolk rate per 100,000	Suffolk count	Comparison
Pupil referral unit	5,400.5	7,714.6	14,814.8	16	Significantly higher than England. Similar to East
State-funded nursery	1,892.9	2,199.6	1,111.1	1	Statistically similar to England & East
State-funded special school	33,648.9	24,633.7	20,639.5	284	Significantly lower than England and East
State-funded secondary	1,754.7	1,725.8	1,919.1	871	Significantly higher than England and East
State-funded primary	1,496.0	1,582.8	1,600.2	914	Statistically similar to England & East
Total	2,167.9	2,006.1	2,004.2	2,086	Significantly lower than England. Similar to East

Figure 3: Pupils with primary SEN ASD, pupil referral units compared to special schools and Suffolk total, rates per 100,000 with 95% confidence intervals, 2015/16 to 2021/22



The number of Suffolk students that had been identified as having ASD increased as students progressed through nursery and primary school, reaching a peak in National Curriculum Year (NCY) 7, the first year of secondary education (Figure 4). In each survey year from 2019/20, there was a marked increase of around 55 students with ASD in NCY 7 when compared to that same cohort the year before (e.g., comparing 2019/20 NCY7 with 2018/19, NCY 6) (Figure 4). These increases were much higher than had been seen for the previous survey years at this age group (average 21).

Each year, a general decrease in the number of Suffolk students with ASD was seen as cohorts progressed through secondary schools, with a further marked decline in NCYs 12, 13 and 14 (Figure 4). The marked decline in NCYs 12, 13 and 14 is primarily because the Department for Education school census (the source of these data) is not completed by colleges, where many pupils go on to for their post-16 education.



Figure 4: Pupils in Suffolk with primary SEN ASD by national curriculum year and survey year

Ethnicity

For Suffolk students with primary SEN ASD in 2021/22, the largest ethnicity group consisted of White British students (83.3%, significantly higher than the percentage of Suffolk pupils as a whole) (Table 8). The percentage of pupils with ASD who were "any other White background" were significantly lower. Caution should be used interpreting these figures as counts are low.

Ethnicity	Count of pupils with ASD	% Pupils with ASD	% Suffolk total pupil population
Any other ethnic group	20	1.0%	1.1%
Asian - any other Asian background	5	0.2%	0.3%
Asian - Bangladeshi	15	0.7%	0.6%
Asian - Chinese	1	0.0%	0.1%
Asian - Indian	14	0.7%	0.8%
Asian - Pakistani	2	0.1%	0.2%
Black - Any other Black background	7	0.3%	0.3%
Black - Black African	13	0.6%	0.5%
Black - Black Caribbean	6	0.3%	0.2%
Mixed - Any other mixed background	58	2.8%	2.8%
Mixed - White and Asian	12	0.6%	1.0%
Mixed - White and Black African	9	0.4%	0.8%
Mixed - White and Black Caribbean	27	1.3%	1.4%
Unclassified	73	3.5%	2.7%
White - any other White background	81	3.9%	6.6%
White - Gypsy/Roma	-	0.0%	0.6%
White - Irish	4	0.2%	0.2%
White - Traveller of Irish heritage	2	0.1%	0.0%
White - White British	1,737	83.3%	79.8%

Table 8: Suffolk pupils with primary SEN ASD compared to Suffolk pupil population, by ethnicity, $2021/22^{20}$

Deprivation

It is known from previous national research that there is a statistically significant association between deprivation and learning disabilities, with children living in more deprived areas being more likely to be identified as having learning disabilities²³. By matching the postcodes of 5,786 pupils (an additional 200 postcodes could not be matched) with a primary SEN of autism to Suffolk LSOAs (2020-22 data), it was possible to ascertain how many lived in areas of relative deprivation (Indices of Deprivation 2019, where 1 = most deprived and 5 = least deprived). This suggests that there is not such a strong association between deprivation and autism, as the distribution follows a more typical pattern, with the lowest percentage of pupils in the most and least deprived areas (IMD 1 and 5, significantly lower than quintiles 2 to 4), and the highest percentage in in middle (IMD 3, significantly higher than the other quintiles) (Figure 5).



Figure 5: Pupils with primary SEN Autism by IMD 2019 quintile, Suffolk, 2020-22 Census

Data from Suffolk's Children's and Young People's Services

At 31 March 2022, 12.9% children in need in Suffolk had a recorded disability (n= 522), statistically significantly similar to England (12.3%). Of these, 33.0% had a record of "Autistic Spectrum Disorder", compared to 39.0% England²⁰. Statistical significance cannot be checked as counts are not published, however prevalence of around a third is markedly higher than the expected 1.6% prevalence in 16-34 year olds, or 1.2% in 5-19 year olds (Table 1, Table 3).

<u>The latest data on children in need</u>, including children looked after by local authorities in England (2021/22) (Table 9), showed Suffolk had a significantly lower percentage of pupils who had a SEN of ASD and were children in need, excluding children on a child protection plan and children looked after (this includes children on child in need plans as well as other types of plan or arrangements, CINO) than the East of England and England. The percentage of children looked after (for at least twelve months, CLA) and children on a child protection plan (excluding children looked after, CPPO) in Suffolk with a primary SEN of ASD was statistically similar to East of England and England (Table 9).

"Diagnosed with autism or Asperger's syndrome" was the second most frequently recorded disability for children in care (June 2023) (n=45, rounded to 5, highest was learning disability n=55). 44.4% of children and young people with this diagnosis recorded (n = 20) were placed in children's homes, significantly higher than for all children in care (8.2%, n=80). Source: unpublished internal data (snapshot) from Children and Young People's directorate.

Table 9: Total number of pupils who are children in need at 31 March with primary type of need: Autistic Spectrum Disorder, 2021-22

Children by type of need	Area	Pupils with SEN	Total pupils	Percentage	Comparison (%)
CINO	England	13,000	139,320	9.3%	
CINO	East of England	990	9,830	10.1%	Higher than England
CINO	Suffolk	51	1,057	4.8%	Lower than England and East of England
CLA	England	1,770	41,940	4.2%	
CLA	East of England	140	3,490	4.0%	Similar to England
CLA	Suffolk	13	492	2.6%	Similar to England and East of England
СРРО	England	800	29,710	2.7%	
СРРО	East of England	40	1,800	2.2%	Similar to England
СРРО	Suffolk	n/a			Suppressed to protect confidentiality

Autism in Suffolk adults

Suffolk County Council data

Local data on learning disabilities in adults in Suffolk were extracted from the Suffolk County Council Adult and Community Services (SCC ACS) customer database in March 2023, for current customers who were receiving support with a need of "Autism (excluding Asperger's Syndrome / High Functioning Autism)" (n=643) or "Asperger's Syndrome / High Functioning Autism" (n=198). 58 customers were recorded in **both groups**, so the total number of individuals is 783.

Significantly higher percentages of SCC ACS customers with a record of autism were in the younger age bands (18-24, 25-64) than all SCC ACS customers (Figure 6). A statistically significantly higher percentage were male (72.7%), compared to 43.0% of all SCC ACS customers.



Figure 6: SCC ACS customers with a record of autism by age band compared to all customers, March 2023

Table 10: Age and sex distribution of Suffolk residents with a record of autism that were active customers of SCC ACS in March 2023

	18-24 years old	25-64 years old	Aged 65 and over	Total
Female	47	163	4	214
Male	117	425	27	569
Total	164	588	31	783

Table 11: Recorded ethnicity groups of Suffolk residents who are active customers of SCC ACS and have a record of autism, compared to the Suffolk population (2021 Census), March 2023

Broad ethnic group	Active autistic customers	Percentage of autistic customers	Percentage of Suffolk population (all ages) (2021 Census)	
Asian, Asian British or Asian Welsh	11	1.4%	2.3%	
Black, Black British, Black Welsh, Caribbean or African	8	1.0%	1.3%	
Mixed or Multiple ethnic groups	14	1.8%	2.3%	
Not available*	10	1.3%		
Other ethnic group	2	0.3%	0.9%	
White	738	94.3%	93.1%	

*Not available includes refused, not recorded, unknown.

Personal Independence Payments

In December 2022, 2,023 people aged 16 or over were recorded in Suffolk as receiving Personal Independence Payments (PIP) with an entitlement reason "Autism Spectrum Disorders" by the Department of Work and Pensions. They represented 6.1% of all Suffolk PIP claimants (significantly higher than East of England 5.5%, and England 5.2%). Three quarters were male, statistically significantly similar to England and the region (76.6% Suffolk, 75.5% East of England, 74.9% England). A lower percentage (31.0%, n=627) were aged 16-19 compared to East of England (35.7%) and England (34.9%) (Figure 7).

Figure 7: People receiving PIP with ASD entitlement by age band (%) and area, December 2022



Trends in diagnosis

Rates of referrals for suspected autism are increasing, especially in people aged under 25. This is in the context of an "exponential increase" in recorded incidence of autism diagnoses in the UK between 1998 and 2018, with the greatest rises in incidence in adults. It is more likely that this is due to increasing diagnosis in "females and higher functioning individuals" than increasing prevalence²⁴.

Experimental data from the mental health services data set show significant increases in referrals in in 2021/22 compared to the previous two years for Ipswich and East Suffolk and West Suffolk areas (Figure 8, Figure 9). This data does not include autism diagnosis activity in community services. Norfolk and Waveney have a different process for diagnosis.

Potential reasons for the increase in referrals include:

- the impact of COVID-19 lockdowns creating backlogs in services
- the impact of COVID-19 lockdowns on individuals and their families²⁵
- the NHS national autism strategy
- greater public awareness, for example through well-known people speaking about their diagnoses
- changes in recording

Figure 8: Suspected autism referrals, people aged under 25, rate per 100,000, Suffolk sub-ICB areas, 2019/20-2021/22²⁶





Figure 9: Suspected autism referrals, people aged 25 and over, rate per 100,000, Suffolk sub-ICB areas, $2019/20-2021/22^{26}$

The increase in referrals links to increases in people waiting 13 or more weeks for a diagnosis (Figure 10). The Ipswich and East Suffolk area also has the highest rates of referrals.



Figure 10: The number of patients with an open "suspected autism" referral in the month that has been open for at least 13 weeks, Suffolk sub-ICB areas²⁶

Impact of delayed diagnosis, or diagnosis in later life

- Late-diagnosed autistic children often have high levels of mental health and social difficulties prior to their autism diagnosis, and tend to develop even more severe problems as they enter adolescence²⁷.
- Delay can affect education (e.g. adjustments aren't made).
- Timely diagnosis can enable a child or young person to understand why they may respond in a specific way.
- Families may experience undue stress while waiting for a diagnosis.
- Delays may mean mental health conditions go undiagnosed.
- Women receiving a diagnosis in later life (aged over 40) reported a change in identity that enabled greater acceptance and understanding of themselves. However, it was painful to adjust so late¹⁰.
- Delayed waiting times are associated with increased financial costs to the NHS and other services. The National Autistic Society have estimated that investing in ASD diagnosis would lead to cost savings for the NHS of up to £337 million over five years, from reduced spending on mental health services²⁸.

Projections of autistic population

The Institute of Public Care (IPC) publish estimates using ONS projected future populations and a 1.0% prevalence rates for autism in adults living in households in England (Table 12). This prevalence rate is taken from the Adult Psychiatric Morbidity Survey (APMS) 2007²⁹, which uses a score of 10 or more on the Autism Diagnostic Observation Schedule (ADOS) to indicate a positive case. This prevalence figure has since been revised, initially because the 2007 APMS did not survey adults with LD³⁰, and then in 2016 based on prevalence figures from 2007 and 2014⁸.

Age band	2020	2025	2030	2035	2040
Aged 18-24	531	520	572	576	547
Aged 25-34	895	871	831	850	912
Aged 35-44	850	900	905	884	845
Aged 45-54	1,007	902	888	937	945
Aged 55-64	1,018	1,106	1,069	973	969
Aged 65-74	929	917	1,035	1,130	1,102
Aged 75 and over	789	968	1,060	1,157	1,295
Total	6,019	6,184	6,360	6,507	6,615

Table 12: People aged 18 and over predicted to have autistic spectrum disorders, by age, projected to 2040^{7,13}

The number of autistic people in Suffolk is predicted to increase to 6,360 by 2030 and to 6,615 by 2040, an increase of 9.9% on levels in 2020. Most of this growth is projected to come in older (65 and over) age categories, with 679 more autistic adults aged 65 and over in 2040 than in 2020. The IPC estimate that over a third (36.2%, n=2,397) of autistic people will be aged 65 or over by 2040 (Figure 11). This will inevitably lead to a change in support needed.



Figure 11: Projected numbers of autistic people in Suffolk by age band, 2020 to 2040

Inequalities

Education

Nationally there is inadequate provision for autistic children in schools: autistic children often can't access the opportunities they needed:

- 40% of parents of said the school did not meet their child's needs,
- 42% of parents stated that their initial request for SEN assessment was refused. 50% of parents stated that it took over a year for school support to be provided.³¹

"My teachers never had any idea how to help with my autism or dissociation, and I couldn't inform them when I was dealing with symptoms of a psychotic episode for a few months" (Suffolk young person quoted in My Health Our Future, Healthwatch Suffolk 2022)³².

Pupils who are taught in mainstream education may have SEN and ASD, and receive support, without needing an Education, Health & Care Plan (EHCP). In Suffolk in 2021/22, less than half of children with a record of ASD as their primary SEN have a statement or EHCP) (47.6%, n = 992), significantly lower than England (56.7%) and the East of England (53.2%) (2021/22 data)²⁰. Around a quarter (25.0%) of Suffolk pupils with a statement or EHCP had a primary SEN ASD, significantly lower than England (31.3%).

The COVID-19 pandemic and control measures had a mixed impact on children and young people with ASD in Suffolk. Elected home schooling increased because of anxieties about going back to school and some children fairing a lot better through being at home²². As at 24 March 2023, 93 pupils in Suffolk were in Elective Home Education: over a third (37.6%, n=35) had a record of ASD.

In Suffolk, significantly higher rates of pupils with ASD attend pupil referral units and special schools (Figure 3). This may be expected, as some pupils with ASD will not have their needs met in mainstream education: special schools cater for such needs. Pupils at Suffolk special schools are required to have an EHCP³³. Pupil referral units teach children who aren't able to attend school and may not otherwise receive suitable education³⁴. In 2021/22, 85.6% of Suffolk students (1,786/2,086) with primary SEN ASD were educated in mainstream schools. 13.6% (284/2086) in special schools, and less than 1% (0.8%, 16) in pupil referral units.

A significantly lower percentage of Suffolk pupils with SEN progressed to Higher Education in 2020/21 compared to England (14.8%, compared to 18.8%) and to Suffolk pupils without SEN $(41.0\%)^{20}$.

Social inequalities

Autistic people are vulnerable to isolation and bullying caused by a lack of opportunities to integrate socially; this exacerbates mental health problems³¹. 40-63% of autistic children are estimated to be bullied³⁵. Healthwatch Suffolk reported that 40% "young people who self-identified as having special educational needs and disabilities (SEND)" had been bullied in school (compared to 27% of their peers), 22% were bullied online (compared to 15%), and 24% had been bullied outside school (15%)³².

Autistic adults experience more behavioural and emotional regulation issues, and are more likely to live with their parents^{36,37}. In 2021, 76% of autistic people aged 16-64 were living with parents, compared to 16.4% disabled people and 19.2% non-disabled people (Office for National Statistics survey)³⁸.

Autistic people are likely to face challenges with social interaction and romantic relationships, and particular issues with puberty, reproductive health and sexual vulnerability or the risk of sexual abuse^{39,40}.

Economic inequalities

A smaller percentage of children with PDD/ASD are in the highest two quintiles of equivalised household income (England)¹⁶.



Figure 12: Percentage of children and young people with PDD/ASD by equivalised household income quintiles, England 2017¹⁶

In England, a higher percentage of children with ASD are in families in receipt of low income benefits (2.8%, compared to 0.7% families not in receipt of benefits) but the percentage of children with ASD is slightly higher in households living in the least deprived areas of deprivation (IMD 2015) (1.5% compared to 1.2% most deprived) (England). Note: "a household was classified as in receipt of 'low income benefits' if any resident adult with parental responsibility for the child reported being in

receipt of any of: Housing Benefit, Working Tax Credit, Income Support, Universal Credit (UC), Job Seekers' Allowance, or Pension Credit. Child Tax Credit (CTC) did not count."¹⁶



Figure 13: Percentage of children and young people with PDD/ASD by neighbourhood deprivation quintiles, England, 2017¹⁶

A significantly higher percentage of children with ASD are eligible for Free School Meals than the Suffolk pupil population (28.1% compared to 19.6%), but significantly lower than the percentage of pupils with ASD eligible for FSM nationally (34.0%) (Suffolk Public Health and Communities analysis od 2021/22 school census data)²⁰.

Employment

Autistic people have the second lowest (29.0%) employment rates nationally. This is significantly lower than employment rates for people with other impairments (except disabled people with severe or specific learning difficulties, 26.2% and mental illness, 30.1%). 53.5% people with disability (aged 16 to 64) are employed, compared to 81.6% non-disabled people³⁷.

Adults with ASD have a greater tendency to be overeducated for their jobs (also known as "underemployment")³⁶. Reasons may include difficulty accessing support to find employment, or recruitment processes that do not support autistic people. Nationally, 31% of employers believe that autistic people would require too much support³¹.

People with high functioning autism reported workplace challenges: communication, social interaction, and stress, together with negative mental and physical health⁴¹.

Access to health care

Autistic young people often have difficulty understanding their own mental health needs and face high levels of stigma when trying to access mental health support⁴².

A review of why people with autism and/or learning disabilities are delayed from discharge in longstay hospital settings or experience very long stays very significant found reported reasons included "the extent or complexity of the individual's needs, or because of system issues such as a lack of suitable services in the community, disputes and issues with funding, poorly designed or implemented discharge or transfer processes, and wider problems with governance, commissioning and inter-agency relationships"⁴³.

Criminal justice system

It is estimated that autistic people are up to seven times more likely than the general population to be involved in the criminal justice system (CJS), as a victim, a witness or a defendant⁴⁴.

The Office for National Statistics has published data on disability and crime in England and Wales in the year ending March 2020. 1 in 4 (23.1%) disabled adults aged 16 years and over experienced crime (including fraud and computer misuse). Confidence intervals were not published, so differences may not be significantly different, but the proportion of people with an impairment described as "socially or behaviourally (for example, associated with autism, attention deficit disorder or Asperger's syndrome)" who had experienced anti-social behaviour (59.8%) was the highest of the ten impairment types (note "learning or understanding or concentrating" was a separate impairment type). 20.0% people with a social or behavioural impairment had experienced domestic abuse (also higher than for the other impairment types)^{45,46}.

75% of autistic adults and 86% of parent/carers reported that they had been visited at least once by the police (responding to a survey by the National Autistic Society)⁴⁷.

Rates of offending among autistic people appear to be similar, or lower, than the general population. However, they appear to be over-represented within CJS settings. The underlying reasons for this are unclear⁴⁸. Survey data suggests autistic people are not always given the support they need during the process, and that the experience may have a more negative impact on autistic peoples' mental health than that of non-autistic people⁴⁹.

A review by the Criminal Justice Inspectorate⁵⁰ estimated 5–7% of those referred to liaison and diversion services have an autistic spectrum condition. Within prisons the prevalence of autistic 'traits' or 'indicators' could be around 16% and 19%, although only 0.5% were recorded as having "autistic spectrum condition".

In Suffolk, a recent inspection of youth justice services (January 2023) recommended that the Suffolk Youth Justice Service partnership board should make "better use of shared data" and "improve understanding of the needs and outcomes for diverse groups of children"⁵¹.

Impact of COVID-19

The COVID-19 pandemic and control measures had a mixed impact on autistic children and young people in Suffolk. ²²

- Some autistic young people felt the pandemic "was autism-friendly, with clear rules and fewer stimuli" while others struggled with uncertainty: "It is really hard not knowing when this is all going to end. Not having a date to work towards."
- "She is walking around with a domestic bottle of sanitizer and if anyone gets near her, she tells them they're in her space. (it's her ASD gone mad)" (parent of young person with autism)
- Visiting restrictions caused significant distress, "even more so to people who may have been less able to process what was happening for one reason or another, such as people with learning disabilities and autism".⁵²

Autism and health

Mortality

From January 2022, LeDeR (Learning from Lives and Deaths Review) includes deaths of people with a diagnosis of autism without LD (publication due 2023). Before then, only the deaths of people with a learning disability were considered, however some of these people were likely to have had autism.

In 2021, the national LeDeR (Learning from Lives and Deaths Review) reported that 49% of deaths of people with a learning disability were avoidable (that is, preventable and treatable causes of death in people under 75 years of age), compared to 22% of the general population⁵³.

Table 13: Median age at death LeDeR*, compared to England population, 2020-21

Sex	England (LeDeR 2020/21)	Suffolk (LeDeR 2020/21)	General population, England (2020)		
Males	61	58	81.8		
Females	60	63.5	85.5		

LeDeR data and reports cover the population aged 4 and above, general population data includes information about children 0-3 years. Data does not include deaths of autistic people who do not have a learning disability.

The median age at death for autistic people is 55 (low-functioning ASD 40 years, compared to high-functioning ASD 63 years) (2016 analysis). This is 27-30 years younger than the population as a whole: the median age at death for people in England in 2020 was 81.8 (males) and 85.5 (females)⁵⁴.

A Swedish study reported epilepsy to be the leading cause of death for autistic people with a learning disability, and suicide to be the leading cause of death for autistic people without a learning disability⁵⁴.

A study of coroners' inquest records found evidence of autism (10.8%) was significantly higher in those who died by suicide than the 1.1% prevalence expected in the UK general alive population⁵⁵. The National Confidential Inquiry into Suicide and Safety in Mental Health (2023)⁵⁶ identified a clinical message: "the role of family and educational settings, and the management of anxiety and autism, are especially important" for people aged under 18.

Other neurodevelopmental and learning disabilities

Studies suggest around 40% of autistic people have a learning disability⁶. Autistic people often also have dyslexia and dyspraxia⁵⁷.

28% autistic people are estimated to have ADHD (7.2% general population)⁵⁸. In 2021/22, experimental figures for England reported 0.1% patients with a diagnosis of autism without a learning disability and 4.8% patients with a learning disability and a diagnosis of autism also had a diagnosis of ADHD⁵⁹.

A statistically significantly higher percentage of pupils with autism (primary SEN) have the following secondary SEN, compared to all Suffolk pupils (2021/22 data)²⁰:

- Multi-sensory Impairment
- Other Difficulty or Disability (not specified)
- Social, Emotional and Mental Health needs
- Speech, Language and Communications needs

• Severe Learning Difficulty

Delays in language development are common in autism, and up to 30% of autistic people are non-speaking (completely, temporarily, or in certain contexts)^{44,60}.

Median overall period prevalence of epilepsy in autistic people has been calculated as 11.2% (median overall period prevalence of autism in people with epilepsy was 8.1%). In 2021-22, experimental figures for England reported 1.7% patients with a diagnosis of autism without a learning disability have a diagnosis of epilepsy, and14.1% patients with a learning disability and a diagnosis of autism⁶¹.

Experimental data suggests patients with a learning disability are 21 times more likely to be diagnosed with autism than those without a learning disability. Figures for sub-ICB areas covering Suffolk:⁶²

- West Suffolk 14.8 times more likely (2021/22 data),
- Norfolk & Waveney 19.4 times more likely (2021/22 data),
- Ipswich & East Suffolk 16.7 times more likely (2020-21 data).

Figure 14: Percentage of patients who have a diagnosis of learning disability or autism, sub-ICB areas serving Suffolk, 2021/22 and 2020/21 (Ipswich and East Suffolk)⁶²



Mental health conditions

NICE estimates that around 70% of autistic people have at least one "psychiatric disorder", which is "often unrecognised"⁶³. Using the estimate of 5,160 autistic people in Suffolk (2022), this might suggest roughly 3,600 also have a mental health condition. 40% have two or more mental health conditions⁴⁴ (estimated 2,060 people in Suffolk).

- 20% with anxiety disorders (7.3% in the general population) that could be around 1,030 autistic people in Suffolk.
- 11% with depressive disorders (4.7% in the general population) that could be around 570 autistic people in Suffolk.
- 4% with schizophrenia and psychotic spectrum disorders (0.46% in the general population) that could be around 200 autistic people in Suffolk.

Autistic people often also have obsessive compulsive disorder, or OCD (estimated by one UK study as 5% of autistic young people aged 4-17)^{57,64}.

There is an association between ASD and food selectivity, although eating problems in people with ASD may not meet the criteria for a specific eating disorder or avoidant/restrictive food intake disorder (ARFID). For example, around half of children with ASD may have eating problems, and it has been suggested that 20% of autistic people may be at risk of ARFID^{65,66}.

A higher percentage of people with anorexia nervosa (AN) may have ASD symptoms than the general population, however it is uncertain whether the ASD symptoms indicate an underlying neurodevelopmental disorder or whether AN may produce autistic-like symptoms^{67,68}. There has been less research on whether there is a higher prevalence of AN (or other eating disorders) in people with ASD – a nationwide cohort study in Denmark found that people with a diagnosis of ASD had a higher risk of AN, but the risk of AN was comparable to the risk in people with major depression^{67,69}.

Around 42% of autistic people are estimated to self-harm, compared to around 8% of children and young people, or 5.9% of adults. "Hand hitting [23%], skin picking and hitting self against objects to be the most common forms of self-injury, whilst self-cutting [3%] was the least common."⁷⁰

A UK study found that 66% of adults with Asperger syndrome (sic, defined in the research as "autism without language delay or intellectual disability") had contemplated suicide, compared with 17% of non-autistic adults⁷¹. Research in the USA suggested that 14% of autistic children experience suicidal thoughts, compared with 0.5% of non-autistic children⁷².

Risk markers for suicidality in autistic people may include "camouflaging and unmet support needs" as well as markers found in the population as a whole: self-harm, unemployment and depression⁷¹.

Wellbeing

Sleep problems are one of the most common complaints in autistic adults⁵⁷, with prevalence rates of sleep problems reported as high as 79%. Sleep quality has been found to predict quality of life in both autistic and non-autistic adults⁷³.

Autistic people are more vulnerable to negative life experiences, which may also impact mental health⁴⁴.

Compared to the general population, autistic people report having a lower quality of life^{42,74}. Being in employment, receiving support, and being in a relationship contribute to positive quality of life, while having mental ill health or more severe autism predicted lower quality of life scores⁷⁴.

Autistic people had the lowest (worst) average score for happiness, the second lowest average score for feeling life is worthwhile and the third highest (where high is worse) for levels of anxiety in the UK (2021 survey data, average wellbeing ratings for disabled people by impairment type)⁷⁵. The number of autistic people that were surveyed was small, so the differences cannot be said to be statistically significant.

Irritability and aggression are more common in ASD (25%) than in other developmental disorders⁶⁰.

Young people with SEND (not broken down to have a lower wellbeing scored (poorer wellbeing) than the Suffolk average, and the 2020 national average³².

Physical health conditions

Autistic people are almost 16 times more likely to have a long-term health condition than people without autism⁷⁶.

Autistic people often also have problems with joints and other parts of the body⁵⁷.

Gastrointestinal disorders are more common in people with ASD: they are more likely to experience constipation and diarrhoea, and 46.8% of autistic people are likely to have any gastrointestinal symptoms⁷⁷; children with ASD are also more likely to experience abdominal pain⁷⁸.

Heart arrhythmias are three times more likely in autistic people than those without⁷⁹.

The prevalence of autoimmune conditions has been found to be higher in autistic people than the general population⁸⁰.

Nearly all medical conditions were significantly more common in autistic adults, including immune conditions, gastrointestinal and sleep disorders, seizure, obesity, dyslipidaemia, hypertension, and diabetes. Rarer conditions, such as stroke and Parkinson's disease, were also significantly more common among autistic adults.⁸⁰ The most common medical conditions were seizures, obesity, insomnia, and constipation. The median number of medical conditions per person was 11⁸¹.

Autistic women are:79

- 1.4 times more likely to have a cardiovascular condition than women without autism
- 1.7 times more likely to have diabetes
- o twice as likely to have a respiratory condition (including asthma)

Health checks and screening

Although autism is not a learning disability, health statistics for autistic people are published as part of the dataset on people with learning disabilities. It is known that, nationally, people with learning disabilities are statistically significantly less likely to receive screening tests, for example for cancer, than those without learning disabilities^{82,83}. Screening can help to reduce health inequalities. The NHS has published experimental statistics on the Health and Care of People with Learning Disabilities⁸⁴: the statistics are classed as experimental as they cover 55.7% of the population and do not include data from GP practices that use SystmOne. Patient coverage by Suffolk CCG for 2021/22:

- 11.9% Norfolk and Waveney
- 21.8% West Suffolk
- 0.0% Ipswich and East Suffolk (4.0% coverage in 2020/21)

Although these data are limited for Suffolk, they are the best available source of data on cancer screening in people with learning disabilities in Suffolk. Figures will also have been affected by the COVID-19 pandemic and lockdown measures.



Figure 15: Standardised prevalence ration (SPR) by type of cancer screening, people with a record of autism, Suffolk CCGs¹⁷

- SPR = 0.5 half as common as expected
- SPR = 2.0 twice as common as expected.

NHS and adult social care service use

Service use SCC ACS

Local data on learning disabilities in adults in Suffolk were extracted from the Suffolk County Council Adult and Community Services (SCC ACS) customer database in March 2023, for current customers who were receiving support with a need of Autism (excluding Asperger's Syndrome / High Functioning Autism) (n=643) or Asperger's Syndrome / High Functioning Autism (n=198). 58 customers were recorded in both groups, so the total number of individuals is 783.

	Autism (excl. Asperger's Syndrome / High Functioning Autism)	Asperger's Syndrome / High Functioning Autism	All ASD	All customers	
People (count)	643	198	783	9,569	
Maximum weekly cost	£11,418.00	£24,672.19	£24,672.19	£24,672.19	
Average weekly cost	£1,245.57	£797.85	£1,167.83	£646.59	
Minimum weekly cost	£0.00	£6.88	£0.00	£0.00	

Table 14: Weekly costs by customer need, SCC ACS, March 2023

Day services, supported housing, and direct payment services were the three service types that were used by the highest numbers of SCC ACS autistic customers (Figure 16), significantly higher than all ACS customers.





Nationally, autistic people have the second lowest employment rates (29.0%) of people with a disability³⁷. Of the 783 SCC ACS autistic customers, only 28 were in paid work (employed, self-employed or in paid volunteering). This was a significantly lower percentage than all ACS customers (16.0% compared to 78.0%), although no information was recorded for 125 autistic customers.

Employment status	Autistic customers (count)	Autistic customers (%)	All ACS customers (%)	Statistical significance (autistic customers compared to all)
Unemployed	562	71.8%	17.5%	Higher
Employed (Paid)	26	3.3%	0.8%	Higher
Self-Employed (Paid)	1	0.1%	0.0%	Similar
Voluntary (Paid)	1	0.1%	0.0%	Lower
Voluntary (Unpaid)	65	8.3%	2.7%	Higher
Retired	3	0.4%	1.0%	Similar
Not recorded	125	16.0%	78.0%	Lower

Table 15: SCC ACS customers by employment status, March 2023

SCC data indicates that 68 (of 900) SCC ACS customers with a record of autism (Asperger's Syndrome / High Functioning Autism and/or Autism (excluding Asperger's Syndrome / High Functioning Autism)) did not have their accommodation status recorded, significantly lower than ACS customers as a whole (7.6% compared to 68.7%).

For ACS customers who did have their accommodation status recorded, a significantly higher percentage of people with a record of autism were in settled mainstream housing with family/friends (42.5%, compared to 31.9% all ACS customers), with significantly lower percentages for:

• Owner Occupier / Shared ownership scheme (3.4% autistic people, 8.0% all ACS),

- Sheltered Housing / Extra care sheltered housing / Other sheltered housing (1.7% compared to 4.0%)
- Tenant Local Authority / Arm's Length Management Organisation / Registered Social Landlord / Housing Association (10.7% compared to 14.6%)

This may reflect the younger age profile of autistic people known to ACS, compared to all ACS customers ().



Figure 17: Accommodation status of SCC ACS autistic customers compared to all SCC ACS customers (excluding null)

A significantly lower percentage of ACS customers who had accommodation status recorded and have autism (excluding Asperger's Syndrome / High Functioning Autism) were tenants (8.5% were Tenant - Local Authority / Arm's Length Management Organisation / Registered Social Landlord / Housing Association, 2.7% Tenant - Private Landlord) when compared to customers with Asperger's Syndrome / High Functioning Autism (18.7% tenants of local authority etc, 5.3% tenants of private landlords).

SCC ACS autistic customers are located across the county (Figure 18), however over a third were linked to Connect areas in Ipswich and Lowestoft (the two largest towns by population in Suffolk). There do not appear to be any other strong geographic trends (Figure 18).



Figure 18: Count of SCC ACS autistic customers by Connect area, March 2023

Carer support

In Suffolk, around five (rounded) carers of autistic people and around five carers of someone with Asperger responded to the Survey of adult carers in England (SACE) 2021-22. These small numbers mean that findings should be interpreted with caution (as it is likely that 15-20% represents one response) but included:⁸⁵

- 40% carers of people with Asperger who had received support or services in the previous 12 months were very satisfied. No one who cared for someone with autism was very or extremely satisfied. 43.0% of Suffolk carers were very or extremely satisfied (36.3% England)
- 20% carers of people with Asperger who had received support or services in the previous 12 months were extremely dissatisfied. No one who cared for someone with autism was very or extremely dissatisfied. 6.3% of Suffolk carers were very or extremely dissatisfied (8.5% England).
- 80% of carers for people with Asperger, and 50% of carers for people with autism, reported their caring role had not caused any financial difficulties over the last 12 months, compared to 57.2% for all carers in Suffolk, and for England.
- 60% of carers for people with Asperger, and 16.7% of carers for people with autism feel they have **enough** encouragement or support compared to 32.0% carers in Suffolk overall (31.5% England).
- 66.7% of carers for people with autism and 20% of carers for people with Asperger feel they have **no** encouragement or support compared to 22.8% carers in England overall.
- There has been a steady decline nationally year on year, in the proportion of carers who felt they have as much social contact as they want, with people they like. In 2021-22, 40% Suffolk carers for people with Asperger felt they had as much social contact as they want, with people they like, compared to 20.6% carers in Suffolk in total, and 28.0% in England. No carers of people with autism agreed with this statement.
- The proportion of carers in England that felt they have little social contact and feel socially isolated increased to 20.9% (20.0% Suffolk). 50% of Suffolk carers for people with autism felt

they had little social contact and felt socially isolated; no carers of people with Asperger agreed with this statement.

Assuring transformation

The purpose of the 'Assuring Transformation' data collection is to ensure public awareness of the NHS commitments to address poor and inappropriate care and achieve the best outcomes for people with a learning disability, or autism, who may also have mental health needs or behaviour that challenges. Data is submitted by commissioners and rounded to 5.

The two ICBs that cover Suffolk also include areas outside Suffolk (North East Essex, all of Norfolk), while the Suffolk TCP (Transforming Care Partnership) does not include the Waveney area of Suffolk (Table 16).

Table 16: Patients by Integrated Care Board (ICB), and by learning disability or autism category, as at end of February 2023⁸⁶

	Total	LD only	Autism only	LD and autism	Neither	LD only	Autism only	LD and autism	Neither
NHS Norfolk &	35	15	10	10	*	47%	29%	24%	*
Waveney ICB									
NHS Suffolk & North	25	10	10	5	*	40%	32%	28%	*
East Essex ICB									
Suffolk TCP*	15	5	5	*	*	46%	38%	*	*
All inpatients, England	2,045		750	820	470	37%	40%	23%	*

*Suffolk Transforming Care Partnership was created between Ipswich and East Suffolk CCG, West Suffolk CCG and Suffolk County Council.

Safeguarding data for people aged 18-64 years

The Safeguarding Adults Collection (SAC)⁸⁷ records safeguarding activity relating to adults aged 18 and over with care and support needs in England. Data are recorded by safeguarding teams based in local authorities and submitted to NHS Digital through a secure data collection system. Figures are rounded to the nearest 5, and numbers below 5 are suppressed. The following tables show the counts of individuals involved in Section 42 Safeguarding Enquiries, that is, where a concern is raised about a risk of abuse and this instigates an investigation under safeguarding procedures in accordance with Section 42 of The Care Act 2014.

Table 17: Individuals Involved in Section 42 Safeguarding Enquiries with "Autism excluding Asperger's Syndrome/ High Functioning Autism", Suffolk and CIPFA nearest neighbours, 2021-22⁸⁷



Table 18: Individuals Involved in Section 42 Safeguarding Enquiries "with Asperger's Syndrome/ High Functioning Autism", Suffolk and CIPFA nearest neighbours, 2021-22⁸⁷



References

- 1. NHS England & NHS Improvement. *People with a learning disability, autism, or both: Liaison and diversion managers and practitioner resources*. https://www.england.nhs.uk/wp-content/uploads/2020/01/Learning-disability-and-autism.pdf (2019).
- 2. National Autistic Society. What is autism. https://www.autism.org.uk/advice-and-guidance/what-is-autism.
- 3. NICE. Autism in adults Definition Background information. https://cks.nice.org.uk/topics/autism-in-adults/background-information/definition/.
- 4. NICE. Autism spectrum disorder in under 19s: recognition, referral and diagnosis CG128. (2017).
- 5. Mencap. What is Autism and Asperger's Syndrome? https://www.mencap.org.uk/learningdisability-explained/conditions-linked-learning-disability/autism-and-aspergers-syndrome.
- 6. Learning disability Autism | Autistica | Autistica. https://www.autistica.org.uk/what-isautism/signs-and-symptoms/learning-disability-and-autism.
- 7. Institute of Public Care. PANSI Projecting Adult Needs and Service Information.

- McManus, S., Bebbington, P., Jenkins, R. & Brugha, T. Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. http://digital.nhs.uk/catalogue/PUB21748 (2016).
- 9. Brugha, T. S. *et al.* Epidemiology of autism spectrum disorders in adults in the community in england. *Arch. Gen. Psychiatry* **68**, 459–465 (2011).
- 10. Leedham, A., Thompson, A. R., Smith, R. & Freeth, M. 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *https://doi.org/10.1177/1362361319853442* **24**, 135–146 (2019).
- 11. NHS Digital. Estimating the Prevalence of Autism Spectrum Conditions in Adults Extending the 2007 Adult Psychiatric Morbidity Survey. (2012).
- 12. NHS Digital. Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022 NDRS. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2021-to-2022 (2022).
- 13. Institute of Public Care. POPPI Projecting Older People Population Information.
- NHS Digital. Autism Spectrum Disorders in Adults Living in Households Throughout England -2007, Report from the Adult Psychiatric Morbidity Survey. 70 http://digital.nhs.uk/catalogue/PUB01131 (2009).
- 15. Zeidan, J. *et al.* Global prevalence of autism: A systematic review update. *Autism Res.* **15**, 778–790 (2022).
- 16. NHS Digital. *Mental Health of Children and Young People in England, 2017 [PAS]*. https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-ofchildren-and-young-people-in-england/2017/2017 (2019).
- 17. NHS Digital. Health and Care of People with Learning Disabilities Experimental Statistics 2020 to 2021. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2020-to-2021 (2021).
- 18. NHS. Patients Registered at a GP Practice April 2021 NDRS. https://digital.nhs.uk/data-andinformation/publications/statistical/patients-registered-at-a-gp-practice/april-2021.
- 19. NICE. Autism in children. https://cks.nice.org.uk/topics/autism-in-children/background-information/definition/ (2021).
- 20. Department for Education. Explore education statistics and data. https://explore-education-statistics.service.gov.uk/.
- 21. Office for Health Improvement and Disparities. Learning Disability Profile. *Public Health Profiles* https://fingertips.phe.org.uk/profile/learning-disabilities.
- 22. Public Health Suffolk. State of Children in Suffolk 2022. https://www.healthysuffolk.org.uk/jsna/socs (2022).
- 23. Emerson, E. Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities. *J. Epidemiol. Community Health* **66**, 218–224 (2012).
- 24. Russell, G. *et al.* Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *J. Child Psychol. Psychiatry Allied Discip.* **63**, 674–682 (2022).
- 25. James Davidson, C., Lodge, K. & Kam, A. The impact of the COVID-19 pandemic on autistic adults-a survey. doi:10.1108/AIA-10-2020-0057.

- 26. Autism Waiting Time Statistics NHS Digital. https://digital.nhs.uk/data-andinformation/publications/statistical/autism-statistics.
- 27. Mandy, W. *et al.* Mental health and social difficulties of late-diagnosed autistic children, across childhood and adolescence. (2022) doi:10.1111/jcpp.13587.
- 28. BMA. Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder. https://www.bma.org.uk/media/2056/autism-briefing.pdf (2019).
- 29. NHS Digital. Adult Psychiatric Morbidity in England 2007, Results of a household survey. 270 http://digital.nhs.uk/catalogue/PUB02931 (2009).
- 30. Brugha, T. *et al. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey.* https://digital.nhs.uk/catalogue/PUB05061 (2012).
- 31. All Party Parliamentary Group on Autism & National Autistic Society. *The Autism Act, 10 years* on: a report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England. (2019).
- 32. Healthwatch Suffolk. My Health, Our Future Phase six (2022). https://healthwatchsuffolk.co.uk/mhof/phasesix/ (2023).
- Suffolk InfoLink | Specialist Education in Suffolk. https://infolink.suffolk.gov.uk/kb5/suffolk/infolink/advice.page?id=5XcR7C-LNUs.
- 34. Pupil referral units: converting to alternative provision academies GOV.UK. https://www.gov.uk/guidance/pupil-referral-units-converting-to-alternative-provisionacademies.
- 35. Bradshaw, J., Turnpenny, A., Beadle-Brown, J., Milton, D. & Murphy, G. *A scoping report on social care for autistic adults*. https://doi.org/10.21955/amrcopenres.1114922.1 (2020) doi:10.21955/AMRCOPENRES.1114922.1.
- 36. Poon, K. K. & Sidhu, D. J. K. Adults with autism spectrum disorders: a review of outcomes, social attainment, and interventions. *Curr. Opin. Psychiatry* **30**, 77–84 (2017).
- 37. Office for National Statistics. Outcomes for disabled people in the UK: 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2021 (2022).
- 38. ONS. Disability and housing datasets. *Office for National Statistics Statistical Bulletin* https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/dat asets/disabilityandhousinguk (2019).
- 39. Mademtzi, M., Singh, P., Shic, · Fred & Koenig, K. Challenges of Females with Autism: A Parental Perspective. *J. Autism Dev. Disord.* **48**, 1301–1310 (2018).
- 40. Dubreucq, M. & Dubreucq, J. Toward a Gender-Sensitive Approach of Psychiatric Rehabilitation in Autism Spectrum Disorder (ASD): A Systematic Review of Women Needs in the Domains of Romantic Relationships and Reproductive Health. *Front. psychiatry* **12**, (2021).
- 41. Hayward, S. M., McVilly, K. R. & Stokes, M. A. Challenges for females with high functioning autism in the workplace: a systematic review. *Disabil. Rehabil.* **40**, 249–258 (2018).
- 42. Crane, L., Adams, F., Harper, G., Welch, J. & Pellicano, E. 'Something needs to change': Mental health experiences of young autistic adults in England.

https://doi.org/10.1177/1362361318757048 23, 477-493 (2018).

- 43. Ince, R., Glasby, J., Miller, R. & Glasby, A. M. 'Why are we stuck in hospital?' Understanding delayed hospital discharges for people with learning disabilities and/or autistic people in long-stay hospitals in the UK. *Heal. Soc. Care Community* **30**, e3477–e3492 (2022).
- Parliamentary Office of Science and Technology. *Autism*. https://researchbriefings.files.parliament.uk/documents/POST-PN-0612/POST-PN-0612.pdf (2020).
- 45. Office for National Statistics. Disability and crime dataset. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/dat asets/disabilityandcrime.
- 46. Office for National Statistics. Disability and crime, UK. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/bul letins/disabilityandcrimeuk/2019.
- 47. National Autistic Society. "My life could be so different" experiences of autistic young people in the youth justice system. 76pp. https://www.autism.org.uk/what-we-do/news/youth-justice-report (2022).
- 48. Chester, V., Bunning, K., Tromans, S., Alexander, R. & Langdon, P. The Prevalence of Autism in the Criminal Justice System: A Systematic Review. *BJPsych Open* **8**, S45–S46 (2022).
- 49. Slavny-Cross, R., Allison, C., Griffiths, S. & Baron-Cohen, S. Autism and the criminal justice system: An analysis of 93 cases. *Autism Res.* **15**, 904–914 (2022).
- 50. Criminal Justice Joint Inspectorate. *Neurodiversity in the criminal justice system: A review of evidence*. https://www.justiceinspectorates.gov.uk/cjji/wp-content/uploads/sites/2/2021/07/Neurodiversity-evidence-review-web-2021.pdf (2021).
- 51. HM Inspectorate of Probation. *Joint inspection of youth justice services in Suffolk*. https://www.justiceinspectorates.gov.uk/hmiprobation/wpcontent/uploads/sites/5/2023/01/Suffolk-YJS-report-v1.0.pdf (2023).
- 52. Suffolk Safeguarding Partnership. *The Appreciative Inquiry into the Impact of Covid on Safeguarding in Suffolk*. https://suffolksp.org.uk/assets/About-Us/Suffolk-Covid-Inquiry.pdf (2021).
- 53. Learning from Lives and Deaths people with a learning disability and autistic people (LeDeR). https://www.kcl.ac.uk/research/leder.
- 54. Hirvikoski, T. *et al.* Premature mortality in autism spectrum disorder. *Br. J. Psychiatry* **208**, 232–238 (2016).
- 55. Cassidy, S. *et al.* Autism and autistic traits in those who died by suicide in England. *Br. J. Psychiatry* 1–9 (2022) doi:10.1192/BJP.2022.21.
- 56. HQIP. National Confidential Inquiry into Suicide and Safety in Mental Health: Annual report. https://www.hqip.org.uk/resource/national-confidential-inquiry-into-suicide-and-safety-inmental-health-annual-report/ (2022).
- 57. Other conditions that affect autistic people NHS. https://www.nhs.uk/conditions/autism/other-conditions/.
- 58. Lai, M.-C. C. *et al.* Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry* **6**, 819–829 (2019).

- 59. NHS Digital. Health and Care of People with Learning Disabilities, Experimental Statistics: 2017 to 2018 [PAS]. *Health and Care of People with Learning Disabilities* https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018.
- 60. Lord, C., Elsabbagh, M., Baird, G. & Veenstra-Vanderweele, J. Autism spectrum disorder. *Lancet* **392**, 508–520 (2018).
- 61. NHS England. Attention deficit hyperactivity disorder (ADHD) and epilepsy 2021-22. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-ofpeople-with-learning-disabilities/experimental-statistics-2021-to-2022/adhd--epilepsy (2022).
- 62. NHS Digital. Key findings Health and Care of People with Learning Disabilities, Health and Care of People with Learning Disability.
- 63. NICE. Autism spectrum disorder in under 19s: support and management. https://www.nice.org.uk/guidance/cg170 (2013).
- 64. Martin, A. F. *et al.* Co-occurring obsessive-compulsive disorder and autism spectrum disorder in young people: prevalence, clinical characteristics and outcomes. *Eur. Child Adolesc. Psychiatry* **29**, 1603–1611 (2020).
- 65. Spek, A. A., van Rijnsoever, W., van Laarhoven, L. & Kiep, M. Eating Problems in Men and Women with an Autism Spectrum Disorder. *J. Autism Dev. Disord.* **50**, 1748–1755 (2020).
- Koomar, T., Thomas, T. R., Pottschmidt, N. R., Lutter, M. & Michaelson, J. J. Estimating the Prevalence and Genetic Risk Mechanisms of ARFID in a Large Autism Cohort. *Front. Psychiatry* 12, 849 (2021).
- 67. Westwood, H. & Tchanturia, K. Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review. *Curr. Psychiatry Rep.* **19**, 1–10 (2017).
- 68. Kerr-Gaffney, J. *et al.* Autism symptoms in anorexia nervosa: a comparative study with females with autism spectrum disorder. *Mol. Autism* **12**, 1–12 (2021).
- 69. Nickel, K. *et al.* Systematic Review: Overlap Between Eating, Autism Spectrum, and Attention-Deficit/Hyperactivity Disorder. *Front. Psychiatry* **10**, 708 (2019).
- 70. Steenfeldt-Kristensen, C., Jones, C. A. & Richards, C. The Prevalence of Self-injurious Behaviour in Autism: A Meta-analytic Study. *J. Autism Dev. Disord.* **50**, 3857–3873 (2020).
- 71. Cassidy, S., Bradley, L., Shaw, R. & Baron-Cohen, S. Risk markers for suicidality in autistic adults. *Mol. Autism* **9**, (2018).
- 72. Mayes, S. D., Gorman, A. A., Hillwig-Garcia, J. & Syed, E. Suicide ideation and attempts in children with autism. *Res. Autism Spectr. Disord.* **7**, 109–119 (2013).
- 73. Halstead, E., Sullivan, E., Zambelli, Z., Ellis, J. G. & Dimitriou, D. The treatment of sleep problems in autistic adults in the United Kingdom. https://doi.org/10.1177/13623613211007226 **25**, 2412–2417 (2021).
- 74. Mason, D. *et al.* Predictors of quality of life for autistic adults. *Autism Res.* **11**, 1138–1147 (2018).
- 75. Disability and well-being Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/dat asets/disabilityandwellbeing.

- 76. Rydzewska, E. *et al.* Prevalence of long-term health conditions in adults with autism: observational study of a whole country population. *BMJ Open* **8**, e023945 (2018).
- 77. Holingue, C., Newill, C., Lee, L. C., Pasricha, P. J. & Daniele Fallin, M. Gastrointestinal symptoms in autism spectrum disorder: A review of the literature on ascertainment and prevalence. *Autism Res.* **11**, 24–36 (2018).
- 78. McElhanon, B. O., McCracken, C., Karpen, S. & Sharp, W. G. Gastrointestinal symptoms in autism spectrum disorder: a meta-analysis. *Pediatrics* **133**, 872–883 (2014).
- 79. Weir, E., Allison, C., Warrier, V. & Baron-Cohen, S. Increased prevalence of noncommunicable physical health conditions among autistic adults. *Autism* **25**, 681–694 (2021).
- 80. Croen, L. A. *et al.* The health status of adults on the autism spectrum. *Autism* **19**, 814–823 (2015).
- Jones, K. B. *et al.* A description of medical conditions in adults with autism spectrum disorder: A follow-up of the 1980s Utah/UCLA Autism Epidemiologic Study. *http://dx.doi.org/10.1177/1362361315594798* 20, 551–561 (2015).
- 82. Osborn, D. P. J. *et al.* Access to cancer screening in people with learning disabilities in the UK: cohort study in the health improvement network, a primary care research database. *PLoS One* **7**, (2012).
- 83. Public Health England. Population screening: reducing inequalities for people with a learning disability, autism or both GOV.UK. https://www.gov.uk/government/publications/population-screening-supporting-people-with-learning-disabilities/population-screening-reducing-inequalities-for-people-with-a-learning-disability-autism-or-both (2021).
- 84. NHS Digital. Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017. https://digital.nhs.uk/catalogue/PUB30167 (2017).
- 85. Personal Social Services Survey of Adult Carers in England, 2021-22 NDRS. https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-servicessurvey-of-adult-carers/england-2021-22.
- 86. NHS Digital. Learning Disability Services Statistics. https://digital.nhs.uk/data-andinformation/publications/statistical/learning-disability-services-statistics.
- 87. Safeguarding Adults Collection NHS Digital. https://digital.nhs.uk/data-andinformation/data-tools-and-services/data-services/adult-social-care-datahub/dashboards/safeguarding-adults-collection.