

# Autism JSNA

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## 1 Introduction

Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others. However, it is essential to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. [With an estimated 700,000 autistic adults and children in the UK, approximately 1% of the population](#), most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK. The latest research from the USA suggests that the [prevalence could be over 2.5%](#).

[The numbers of people affected by autism are not dissimilar to the number of people with dementia](#). The Department of Health, in 2010, indicated [that it is a source of social, economic and health inequality in England](#).

Autistic people of all ages, ethnicities and genders. Inequalities experienced because of disability may interact with discrimination and barriers based on ethnicity, beliefs, sex, gender, sexual orientation, age, pregnancy and maternity, marital status and socio-economic disadvantage. There is an Equalities Impact Assessment to sit alongside this Strategy to summarise how we aim to address these issues.

Autistic people see, hear and feel the world differently from other people. Autism varies widely and is often referred to as a spectrum condition because of the range of ways it can impact people and the different levels of support they may need across their lives. Autism is not a learning disability, though around **4 in 10** autistic people have a learning disability.

Some autistic people will need little or no support in their everyday lives, while others may have co-occurring conditions and need high levels of care, such as 24-hour support in residential care. People may need to be empowered with various things to form friendships, cope at school, manage at work, or get out and about in the community. Wider communities and society should adapt to be inclusive of autistic people.

In this strategy, we also talk about neurodiversity, which refers to how the brain works and interprets information. Neurodiversity uses the social model of disability and considers autism a natural variation rather than a disorder that leads to different ways of thinking and behaving that can be advantageous in some circumstances and disadvantageous in others.

There are no definitive numbers regarding the number of autistic people, either adults or children. Any information about the possible number of autistic people in the community is based on epidemiological surveys. The [website](#) offers some interesting data and facts about autism:

- **34%** of children on the autism spectrum say that the worst thing about being at school is being picked on.
- **63%** of children on the autism spectrum are not in the kind of school their parents believe would best support them.



- **17%** of autistic children have been suspended from school. **48%** had been suspended three or more times; **4%** had been expelled from one or more schools.
- **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.
- At least **one in three** autistic adults is experiencing severe mental health difficulties due to a lack of support.
- Only **16%** of autistic adults in the UK are in full-time paid employment, and only **32%** are in some paid work
- Only **10%** of autistic adults receive employment support, but **53%** say they want it
- Around a **third of people with a learning disability may also be autistic**
- Between **44 and 52%** of autistic people may have a learning disability
- **Five times** as many males as females are diagnosed with autism. There is increasing evidence that there is a significant underdiagnosis of autism in females

The estimated number of autistic people in Northampton is derived from several sources:

### 1.1 Joint Strategic Needs Assessment (JSNA)

- National prevalence figures
- Data from adult and children's social care
- The Schools Census
- Data submitted to Public Health England as part of the 2018 Autism Self-Assessment

### 1.2 Co-occurring conditions

The National Institute for Health and Care Excellence (NICE) estimates that around **70%** of autistic people have an additional condition, which is "often unrecognised". The main conditions that co-occur more frequently in autistic people compared with the general population include:

- Mental health conditions Research suggests that **70%** of autistic people have a mental health condition and that **40%** have two or more.
- Autistic people are **up to four times** more likely to have anxiety disorder and twice as likely to have depression.
- Research has shown that autistic people are more vulnerable to negative life experiences, which may also affect mental health.
- Compared to the general population, autistic people report having a lower quality of life.
- Research shows that suicide is a major cause of early mortality in autistic people.



### 1.3 Neurodevelopmental conditions

These are caused by differences in early brain development and affect how a person processes information, thinks, or learns. Autism is one such condition, and it is common for autistic people to have other neurodevelopmental conditions. These include:

- General learning disabilities (affecting between **15%** and **30%** of autistic people).
- Specific learning difficulties (such as dyslexia and attention-deficit hyperactivity disorder).
- Other conditions such as epilepsy.

Language development delays are common in autism, and up to **30%** of autistic people are non-speaking (completely, temporarily, or in certain contexts).

Historically, autism, both within adults and children, has been seen as being a specialist area requiring input from (often) specialist health, education and social care provision. The reality is very different; in respect of both NHS and Local Authority provision, a person with autism is as likely (or more likely) to require support from and come into contact with day-to-day services, library staff, front-line Local Authority staff, receptionists in health centres, GPs, staff in A&E than with specialist staff within social and health care. Whilst this strategy looks at some areas that relate to the need for specialist input and provision, it also highlights that this is not a strategy relating solely to social care or specific areas of health care. Still, it is a Northamptonshire-wide strategy that needs to be supported by all public services in Northamptonshire.



1 Artwork by Cheryl Stafford

## 2 National Context

### 2.1 National strategy for autistic children, young people and adults: 2021 to 2026

The [recently published national strategy](#) replaces “[Think Autism](#)”, extending the scope of the strategy to autistic children and young people. This sets out the ambitions of the national government and actions for local government, the NHS, and other public institutions on how to improve the lives of autistic people in the next five years.

Around £75 million in funding and an implementation plan have been announced for year one of the strategy.

The strategy covers the following six priority areas, though similar to the areas outlined under “Think Autism, including:

- Improving societal understanding and acceptance of autism.
- Improving access to education and supporting positive experiences of transition.
- Improving employment outcomes for autistic people
- Addressing healthcare inequities.
- Ensuring the right support is available for autistic people to live well in the community.
- Enhancing and improving available support for autistic adults and youth in the criminal and youth justice systems.

### 2.2 NHS Long Term Plan

The [NHS Long Term Plan](#) outlines six priority areas of action (and associated actions) to improve the health, longevity and quality of life of autistic people and people with learning disabilities.

There has been a [40% increase in referrals for people waiting for an autism assessment between June 2022 and June 2023](#). One hundred forty-three thousand people are waiting, and **82%** have been waiting for over 13 weeks. There are around **4,000** new referrals each month.

Since March 2015, there has been a **96%** increase in autistic people without a learning disability entering inpatient Mental Health services.



## 3 Local Context

### 3.1 Demography

At the time of the 2021 Census, Northamptonshire was home to **785,241** people. **359,522** people live in North Northamptonshire. **425,725** people live in West Northamptonshire.

The gender split of the population in both North and West Northamptonshire is **49%** male and **51%** female.

For more demographic data, please visit the Local Insight web pages for [North Northamptonshire](#) and [West Northamptonshire](#).

We estimate there to be somewhere between **8,500** and **11,000** people with autism, diagnosed and undiagnosed, in Northamptonshire, **4,000** and **5,000** in North Northamptonshire and **4,500** and **6,000** in West Northamptonshire. These figures are examined in more detail in the next section.

## 4 Level of Need

### 4.1 Prevalence of Autistic Spectrum Disorders

- Estimates suggest that between 1.5 and 1.76% of children and young people and between 1 and 1.3% of adults are autistic.
- We estimate there to be between 8,514 and 11,032 people with autism in Northamptonshire.
- We estimate there to be between 4,048 and 5,054 people with autism in North Northamptonshire.
- We estimate there to be between 4,465 and 5,979 people with autism in West Northamptonshire.



2 Artwork by Otto Morrison

## 5 Children and Young People

- We estimate there to be between **2,444** and **3,154** children and young people with autism in Northamptonshire.
- We estimate there to be between **1,124** and **1,455** children and young people with autism in North Northamptonshire.
- We estimate there to be between **1,320** and **1,700** children and young people with autism in West Northamptonshire.

### 5.1 Northamptonshire Schools Census

According to the School Census of 2022, **2,262** children have an autistic spectrum disorder. This figure represents an increase of **27%** over the total recorded in 2020 (**1,776**) and **62%** over the number in 2017 (**1,396**). [Research has found](#) that this increase is due to increased autism awareness and a better understanding of what to look for. Please note that the categorisation within this census is not a formal diagnosis:

Need	2017	2020	2022
<b>MLD (Moderate Learning Difficulty)</b>	3,014	2,715	2,594
<b>SPLD (Specific Learning Difficulty)</b>	1,908	2,349	2,790
<b>SLD (Severe Learning Difficulty)</b>	459	482	508
<b>PMLD (Profound &amp; Multiple Learning Difficulty)</b>	124	142	110
<b>SEMH (Social, Emotional &amp; Mental Health)</b>	2,675	3,110	3,401
<b>SLCN (Speech, Language &amp; Communication Needs)</b>	2,330	2,887	3,428
<b>ASD (Autistic Spectrum Disorder)</b>	1,396	1,776	2,262
<b>OTH (Other Difficulty / Disability)</b>	643	889	1,008
<b>NSA (No Specific Assessment)</b>	583	530	840
<b>PD (Physical Disability)</b>	426	472	519
<b>HI (Hearing Impairment)</b>	256	332	379
<b>VI (Visual Impairment)</b>	164	198	199
<b>MSI (Multi-Sensory Impairment)</b>	20	96	82

Table 1 Northamptonshire School Census 2017, 2020 and 2022

## 5.2 OHID Known Numbers

The Office for Health Improvement and Disparities statistics show there are **1,781** children in Northamptonshire known to have autism by their school ([2020](#)). This represents **1.5%** of the school population. That figure of **1.5%** is statistically significantly lower than the national average of **1.8%**. The regional average in the East Midlands is **1.77%**. If we were to apply those proportions to the 2021 Census population aged 5 to 18, that would produce figures of **820** children in North Northamptonshire and **960** in West Northamptonshire.

If we apply that **1.5%** figure to the whole population of Northamptonshire aged between 5 and 18, that gives us an estimate of **2,026**, a difference of **245—937** in North Northamptonshire and **1,089** in West Northamptonshire.

## 5.3 Children aged 0 to 4

There are no published figures for very young children aged 0 to 4 years, so we have used the above prevalence estimates and applied them to the 0 to 4 population of Northamptonshire at the time of the 2021 Census to produce an estimate. This suggests that between **663** and **777** young children could have an autistic spectrum disorder in Northamptonshire. In North Northamptonshire, the estimate is between **303** and **356**; in West Northamptonshire, the estimation is between **360** and **422**.

## 5.4 Further studies

A 2021 [survey of children by Newcastle University](#) found that autism was most prevalent in black schoolchildren (**2.1%**) and lowest in Roma/Irish Traveller children (**0.85%**). It also noted that children with an autism record in schools were **60%** more likely to come from a disadvantaged background and **36%** less likely to speak English.

Applying the **1.76%** prevalence to the population of Northamptonshire aged 5 to 18 gives us an estimate of **2,377**. **1,099** in North Northamptonshire and **1,278** in West Northamptonshire. This estimate is **33%** higher than the number of children known by their schools to be autistic in the OHID statistics.

## 6 Adults

- We estimate there to be between **5,800** and **7,985** adults aged **18** and over with autism in Northamptonshire.
- We estimate there to be between **2,655** and **3,645** adults aged **18** and over with autism in North Northamptonshire.
- We estimate there to be between **3,145** and **4,340** adults aged **18** and over with autism in West Northamptonshire.

### 6.1 POPPI and PANSI

[POPPI](#) and [PANSI](#) predict there to be around **5,800** adults with autistic spectrum disorders living in Northamptonshire. **1,320** of whom are aged 65 and over—**2,655** in North Northamptonshire and **3,145** in West Northamptonshire.

### 6.2 Adult Psychiatric Survey

POPPI and PANSI use the estimated prevalence of autism from the [2007 Adult Psychiatric Survey](#). This survey found rates of prevalence of autism of **1.1% in 14 to 44-year-olds**, **0.9% in 45 to 74-year-olds** and **0.8% in over 75s**. The lower prevalence rates in the older populations are [most likely due to under-diagnosis and lack of recognition of the condition in older cohorts](#). Overall, the rate for all adults was found to be **1%**. Using these three prevalence rates for the population aged 18 and over produces an estimated **6,005** adults with Autism in Northamptonshire. **2,733** in North Northamptonshire and **3,271** in West Northamptonshire.

A [follow-up](#) estimated the prevalence of autism to have increased to **1.1%**. This rate of prevalence produces an estimated **6,757** autistic people aged 18+ in Northamptonshire. **3,085** in North Northamptonshire and **3,672** in West Northamptonshire.

[A further study in 2016](#) used experimental statistics to estimate the prevalence of autism at **0.8%** but noted that it could be as high as **1.3%**. Details of the limitations of these experimental statistics are contained within the published report. Using these prevalence estimates, this gives us an estimate of between **4,914** and **7,985** adults aged 18 and above with Autism in Northamptonshire. For North Northamptonshire, this estimate is between **2,243** and **3,645**; in West Northamptonshire, this estimate ranges between **2,671** and **4,304**. Given the evidence and analysis described previously, we will discount the lower figure and use the POPPI/PANSI estimate as the lower estimate.

Whilst autism is known to impact both males and females, girls and women are [disproportionately less likely to receive a diagnosis](#) and are [considerably more likely to receive a 'late diagnosis'](#), even in the presence of symptoms of equal severity. Current UK

and international evidence reflect that the rate of males diagnosed with autism is **three to five times** higher than for females. **90%** of the adults predicted to have autism by POPPI/PANSI are male.

Please note that people aged 18 have been counted twice in the children/adult breakdown but only once in the total, so as a result of this and rounding up/down, adding these totals will not produce the result at the top of this section.

## 7 Projected need

### 7.1 Children and young people

The following projections result using the **1.5** and **1.78%** prevalence estimates mentioned earlier and applying these estimates to the latest Office for National Statistics Population Projections.

<b>1.5% prevalence</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	693	664	664	681	714
<b>5 to 17</b>	1,919	2,025	1,981	1,918	1,920

*Table 2 Autism projection estimates in Northamptonshire for ages 0 to 4 and 5 to 17 using 1.5% prevalence.*

<b>1.78% prevalence</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	823	788	788	808	847
<b>5 to 17</b>	2,277	2,403	2,531	2,276	2,279

*Table 3 Autism projection estimates in Northamptonshire for ages 0 to 4 and 5 to 17 using 1.78% prevalence.*

The following two tables show the percentage change compared to the 2020 estimate for 2025, 2030, 2035 and 2040:

<b>% change from 2020 (1.5%)</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	4%	-4%	-2%	3%
<b>5 to 17</b>	6%	3%	0%	0%

*Table 4 Percentage change in autism prevalence ages 0 to 4 and 5 to 17 in Northamptonshire compared to 2020 using 1.5% prevalence.*

<b>% change from 2020 (1.78%)</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	-4%	-4%	-2%	3%
<b>5 to 17</b>	6%	11%	0%	0%

*Table 5 Percentage change in autism prevalence ages 0 to 4 and 5 to 17 in Northamptonshire compared to 2020 using 1.78% prevalence.*



The final two tables in this section show the percentage change compared to the last data point, for example, the change between 2020 and 2025, then between 2030 and 2025 and so on:

<b>% change from previous (1.5%)</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	-4%	0%	-2%	3%
<b>5 to 17</b>	6%	-2%	-3%	0%

Table 6 Percentage change in autism prevalence ages 0 to 4 and 5 to 17 in Northamptonshire compared to the previous data point using 1.5% prevalence.

<b>% change from last (1.78%)</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>0 to 4</b>	-4%	0%	3%	5%
<b>5 to 17</b>	6%	5%	-10%	0%

Table 7 Percentage change in autism prevalence ages 0 to 4 and 5 to 17 in Northamptonshire compared to the previous data point using 1.78% prevalence.

## 7.2 Adults

POPPI and PANSI project an increase in the number of people with autism in Northamptonshire to rise by almost **1,000** or by **17%** over the next 20 years. As we've seen earlier, autism prevalence estimates can vary by **30%** over the POPPI/PANSI analysis.

## 7.3 Autistic Spectrum Disorders

<b>Northamptonshire</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>18-24</b>	540	546	625	648	614
<b>25-34</b>	921	922	885	920	1,005
<b>35-44</b>	985	1,051	1,076	1,067	1,024
<b>45-54</b>	1,077	1,034	1,063	1,025	1,143
<b>55-64</b>	954	1,057	1,060	1,025	1,058
<b>65-74</b>	759	760	870	961	967
<b>75+</b>	561	701	779	856	974
<b>Total</b>	5,797	6,071	6,358	6,502	6,785

Table 8 Autistic Spectrum Disorder Estimates 2020 to 2040

The most significant increases in adults living with autism are expected to be in older cohorts, most notably people over the age of 75. The following table shows the percentage change from the 2020 estimate.



<b>% change from 2020</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>18-24</b>	1%	16%	20%	14%
<b>25-34</b>	0%	-4%	0%	9%
<b>35-44</b>	7%	9%	8%	4%
<b>45-54</b>	-4%	-1%	-5%	6%
<b>55-64</b>	11%	11%	7%	11%
<b>65-74</b>	0%	15%	27%	27%
<b>75+</b>	25%	39%	53%	74%
<b>Total</b>	5%	10%	12%	17%

Table 9 Autistic spectrum disorders estimate percentage increase from 2020 prediction.

The fastest increase rates are expected within 5 to 10 years of the 2020 predictions. The number of older people will likely increase between 2020 and 2025. The last table in this section shows the percentage change from the previous data point, for example, the change between 2020 and 2025, then between 2030 and 2025 and so on:

<b>% change from previous</b>	<b>2025</b>	<b>2030</b>	<b>2035</b>	<b>2040</b>
<b>18-24</b>	1%	14%	4%	-5%
<b>25-34</b>	0%	-4%	4%	9%
<b>35-44</b>	7%	2%	-1%	-4%
<b>45-54</b>	-4%	3%	-4%	12%
<b>55-64</b>	11%	0%	-3%	3%
<b>65-74</b>	0%	14%	10%	1%
<b>75+</b>	25%	11%	10%	14%
<b>Total</b>	5%	5%	2%	4%

Table 10 Autistic spectrum disorder estimates increase on the previous five-year estimate.

## 8 Population characteristics

### 8.1 Common comorbidities

Autistic [children, young people](#) and [adults](#) are considerably [more likely to develop a physical or mental health condition than those who are not autistic](#).

Notably, no source examined health conditions in autistic older adults; this constitutes a major gap in the evidence, given that the burden of many health problems and the need for support both increase with age.

While not exhaustive, this review identified several groups of conditions which have been confirmed to co-occur with autism across independent studies, including:

- physical health conditions (tooth decay and gum disease; epilepsy; hypertension and high blood cholesterol; allergies; reproductive system diagnoses).
- mental health or other neurodevelopmental conditions (anxiety, depression, ADHD, alexithymia, eating disorders).
- [Evidence of potential gender disparities in the risk for certain health conditions](#) may be considered when planning and commissioning preventive health services.
- [Hypermobility has high co-morbidity](#)

Particularly concerning is the considerable burden of [mental health conditions faced by autistic people and high rates of suicide relative to the general population](#).

Even more so when coupled with findings from elsewhere in this review, which indicate substantial disparities in access to health and care services (particularly for mental health services) and a lack of support after diagnosis for [children, young people](#) and [adults](#).

Themes around a lack of access to mental healthcare, the ability of mental health services to tailor to autism needs, and a lack of post-diagnostic support services were consistent across published academic and grey literature.

Concerningly, robust evidence also suggests a considerably higher rate of [suicide](#) and [self-harm](#) in autistic people.

### 8.2 Camouflaging and masking

[The emerging literature on camouflaging or masking behaviours](#) (i.e., strategies to mask the symptoms of autism in social situations) has potential implications for how autism is understood and recognised within health and care settings.

While empirical studies on the health risks of camouflaging have not yet been conducted, [qualitative literature](#) has explored the consequences, including physical and emotional exhaustion, as reported by autistic interviewees.

There is an [emerging body of evidence concerning autistic adults' \(particularly females\)](#) use of conscious or unconscious strategies to minimise the appearance of autistic traits within social settings or 'camouflaging'.

Examples of these "behavioural coping strategies to conceal symptoms" given by [a recent narrative review](#) include mirroring facial expressions or other non-verbal gestures in conversation. This concept has been [proposed as one candidate explanation](#) for lower rates of diagnosis in autistic women and girls.

[The narrative review referenced earlier](#) outlines that this area of research is emergent and has largely explored developing methods to measure this concept, and qualitative investigations of camouflaging behaviour among autistic women and girls.

There is also an emerging body of qualitative evidence around the potential physical and emotional consequences of maintaining this camouflage.

The summary of this report notes that *"Consequences [...] included physical and emotional exhaustion, often requiring time alone to recover; issues around identity and authenticity [...] and difficulty accessing support and diagnosis."*

### 8.3 Quality of life

[Systematic](#) and [narrative reviews](#) show that autistic adults may experience lower scores on quality of life (QoL) measures.

Widespread use of QoL measures that have not been validated for autistic adults may give '[misleadingly low or high scores](#)'. A crucial need is to develop appropriate measures to understand what matters to autistic people regarding QoL.

### 8.4 General health and mortality

Population studies show poorer general health and health status in autistic [children](#) and [young people](#), and there is limited research which directly assesses [autistic adults' physical health](#).

Evidence from more [recent cohort studies](#) shows [higher mortality levels](#) in autistic people.

### 8.5 Family, carer and sibling outcomes

Evidence shows lower [Quality of Life \(QoL\)](#) (subjective [mental](#) and physical health) for parents/ carers and [siblings](#) of autistic children.

## 8.6 Employment and education

[There is considerable evidence](#) of disparities in education and employment outcomes for autistic adults (by gender, socioeconomic status and ethnicity).

Several grey literature sources show [poorer post-secondary education outcomes](#) and high [un-and-underemployment for UK autistic graduates](#).

We spoke with local stakeholders who told us that supported employment provision is often based on pan-disability, except for IPS and IAPT, which focus on mental health. Whilst mainstream employment support is available to people who are autistic, it is believed that specific provision is necessary and would support many more people to achieve their learning and employment potential. To achieve this, we would first need to understand how many people need this support and with data of limited value, predicting support needs is difficult, so the proper support for the right person at the right time cannot happen. Capturing condition-specific data and details would help us understand what support could and should look like and the more appropriate allocation of funds and support.

## 8.7 Criminal justice system (CJS) and related settings

[Conflicting findings](#) were identified [across sources](#) as to whether autistic people are [over-represented](#) within the CJS, though autistic people are overrepresented in secure psychiatric settings. There is also a lack of gender-sensitive autism screening tools for identifying autism in CJS.

[UK-based surveys](#) highlight discrepancies in the experiences of autistic people, carers and policing professionals in levels of satisfaction reported.

[Qualitative evidence examining the contributory factors reported by autistic people leading up to their arrest](#) points to the “accumulation of unmanageable stress and a lack of understanding and access to wider support”.

## 8.8 Barriers and facilitators

Several common [barriers](#) to [accessing](#) health and care services (including diagnostic services) were identified, including sensory sensitivities, communication difficulties, lack of autism knowledge, and waiting times.

## 8.9 Access

There is [considerable evidence that](#) autistic people experience disparities in access to health and care services.

[Several sources](#) describe disparities in access to transition-related services and diagnosis and support services by [ethnicity](#) and [socioeconomic status](#).

Access to mental health services appropriately tailored to autistic peoples' needs emerged as a major area of concern for both [children and young people](#) and [adults](#).

## 8.10 Autism diagnostic services

A [recent systematic review](#) highlights, "The evidence supporting racial, ethnic, and economic disparities in ASD diagnosis and service access is strong and has been replicated across multiple studies.

[Wider qualitative research](#) has also highlighted the need to tailor diagnostic services to be more culturally and linguistically sensitive in light of barriers to access.

## 8.11 Post-diagnostic support services

[Available evidence](#) points to a lack of [post-diagnostic support](#) services. Locally, there is limited support directly after diagnosis, and independent voluntary community social enterprises offer peer support.

## 8.12 Gender

A 2021 [survey of children by Newcastle University](#) suggests the prevalence of autism to be **1.76%**, **2.8%** in boys and **0.6%** in girls.

Whilst autism is known to impact both males and females, [girls and women are disproportionately less likely to receive a diagnosis](#) and are [considerably more likely to receive a 'late diagnosis'](#), even in the presence of symptoms of equal severity. **76%** of autistic patients accessing inpatient mental health services between 2022 and 2023 aged under 18 were female; by age 18 to 24, this falls to **46%**, and over 25 falls further to **22%**.

Current UK and international evidence outlined below reflects that the rate of males diagnosed with autism is three to five times higher than for females.

- Of **25,063** individuals with a recorded autism diagnosis, [only around 20% of those were female](#). Follow-up analyses also reflect a **3:1 male-to-female ratio** in prevalence rates at ages 10 and 11 (**4.4%** for boy's vs **1.1%** for girls).

- Rather than reflecting an increased incidence of autism in men relative to women (i.e. that autism is more common in men than women), it is thought that the [signs of autism in women and girls may be under-recognised and under-diagnosed](#).

### 8.12.1 Gender identity and sexual orientation

[Available evidence](#) indicates that there is currently no reliable estimate of the relative proportion of autistic individuals who identify as LGBTQ+. This is because this kind of data is seldom collected in a way that enables robust comparisons, as many large population-based studies do not collect information on autism gender identity or sexual orientation.

While this area of research is emergent, an [earlier systematic review covering articles published between 1966 and 2015](#) indicates that autism may be more prevalent in children and adolescents experiencing gender dysphoria compared to the general population. However, there is limited research concerning adults.

More recently, [researchers at the Autism Research Centre in Cambridge](#) have conducted the largest analysis to date concerning gender identity and autism.

Compared to those who identify as cisgender (someone whose gender identity matches the sex they were 'assigned' at birth (Stonewall)), people who identify as transgender or gender-diverse are between three and six times as likely to be autistic.

### 8.13 Ethnicity

While evidence on the association between ethnic background or ethnicity and autism prevalence is somewhat conflicting, it appears that across the international evidence base, there are differences in the prevalence of autism between ethnic groups.

Specifically, some studies indicate that non-white children are less likely to receive an autism diagnosis, which may indicate disparities in access to diagnostic services or under-identification. In the UK and globally, there is also a lack of research concerning the experiences of ethnically diverse populations who are autistic.

Findings from several population-based studies point to differences in how prevalent autism is among different ethnic groups:

- [One study conducted in Scotland](#) found that children and young people with autism were more likely to be of Caucasian ethnicity.
- US-based work by [Christensen et al in 2017](#) also highlighted lower autism prevalence in children from a Black or Hispanic ethnic background.
- [Magen-Molho et al.](#) identified strong associations between ethnicity and autism prevalence; specifically, autism prevalence was around three times lower in those whose ethnic background was Arab or non-Israeli in 2020.



Findings from the [largest case-control cohort study concerning autism and ethnicity to date](#) (using data from the Spring School Census National Pupil Database) show consistent differences in prevalence rates across ethnic groups. Specifically, in a large sample of children and young people, two ethnic groups were identified as being more likely to have an autism diagnosis recorded in the educational system compared to white pupils:

- Black pupils were **26%** more likely to be recorded as having an autism diagnosis and had the highest prevalence rate overall (**2.11%**).
- Chinese pupils were **38%** more likely to be recorded as having an autism diagnosis.

Several groups were also indicated to have a lower prevalence of autism or be less likely to have an autism diagnosis recorded:

- Roma/Irish Traveller pupils were around **60%** less likely to be recorded as having an autism diagnosis and had the lowest prevalence rates of autism overall (**0.85**).
- Asian pupils and pupils from any other ethnic group were less likely to have autism compared to White pupils.
- This conflicts with US and international evidence showing lower prevalence rates of autism in Black and other minority ethnic groups.

## 9 Physical health conditions and disabilities

### 9.1 Children

[Available evidence](#) highlights a higher burden of physical disabilities, sensory conditions and physical health conditions in autistic children and young people compared to non-autistic children and young people.

For example, a [whole country population observational study conducted in Scotland](#) found that compared to the general population, conditions such as deafness/ partial hearing loss, blindness/ partial sight loss and other physical disabilities were between **5 and 16 times more prevalent** in autistic children; mental health conditions were **16 times more prevalent** in autistic children and young people.

### 9.2 Adults

Several secondary sources highlight a lack of literature related to the physical health of autistic adults. A 2016 scoping review by [Cashin et al](#) outlines that very few primary research studies assess the health status and physical health of autistic adults. A 2020 study by [Kassee et al](#) also reflects this as the first scoping review to examine the physical health of autistic women and girls.

Multiple sources also point to a clear need to conduct further research to understand how physical health changes across the lifespan for autistic [adults](#), [particularly for older adults](#). Notably, very few studies have [shown this](#).

### 9.3 Mental health conditions

A [meta-analysis of 96 prevalence studies](#) highlights that common mental health conditions are highly prevalent in autistic people, more so than in the general population.

#### 9.3.1 Alexithymia

Autism has also been found to co-occur frequently with alexithymia (defined as difficulties in identifying, describing or expressing, and distinguishing between different emotions and internal or bodily sensations).

#### 9.3.2 Depression

Several published academic secondary sources indicate considerably [elevated prevalence rates of depressive disorders and symptoms of depression](#) in autistic adults and young people.

### 9.3.3 Anxiety

Several sources suggest a higher rate of anxiety disorders in autistic children, young people and adults.

Specifically, [Autistica points to previous research](#) to suggest that anxiety is one of the most common mental health issues, affecting four of every ten autistic children.

A more recent meta-analysis by [Lai et al in 2019](#) shows the pooled prevalence of anxiety disorders in autistic adults at around 20%.

The prevalence rate of anxiety disorders in autistic people is concerning, as co-occurring anxiety may [reportedly worsen or exacerbate core autism symptoms such as social challenges and sensory sensitivity](#).

## 10 Employment and workplace outcomes

### 10.1 Published academic literature- secondary sources.

[An early narrative review by Chen et al.](#) in 2015 highlights several aspects of poorer employment outcomes that are consistent with findings from international sources:

- Unemployment: High rates of unemployment (ranging from **40 – 80%**) are indicated across several international studies.
- Underemployment: Autistic individuals who are employed tend to be paid less and may have limited weekly working hours or work in part-time or voluntary roles. For example, a longitudinal study highlighted by the authors followed 66 autistic adults for ten years, finding that only six per cent of individuals had 'competitive jobs', while no adults worked in full-time roles. Other longitudinal research cited (n=68) mirrors this, with only two participants working on full-time salaries.

### 10.2 Grey literature

Findings from a series of focus groups and a UK survey (n=2,080 autistic adults or proxy responses), conducted as part of the [National Autistic Society's \(2016\) work](#) to understand the employment gap, suggest disparities in outcomes and experiences around:

- Employment or getting a job. The full-time employment rate for autistic people is around **16%**; combined with the rate of part-time employment (**16%**), only **32%** of adults in this large survey were employed. About **40%** of respondents reported having never worked. These figures are considerably lower than the rate of adults without disabilities in full-time employment (**80%**).
- Getting a job matching the person's skills and desire to work. Around **40%** reported part-time employment and wanting to work more hours; about **51%** of those in employment also reported being overqualified for their job.
- Employers assumed autistic people would want jobs that do not involve social interaction or that they favour jobs that require technical skills and attention to detail. This is not the case for all autistic people, as this survey showed that for **11%** of respondents, their ideal industry was the arts industry, and **10%** wanted to work in IT. In contrast, smaller proportions indicated administrative or office work (**9%**), research development or library (**7%**) or museum-based roles (**7%**).

## 11 Barriers and facilitators to healthcare access

### 11.1 Published academic literature- secondary sources.

A 2019 UK-based systematic review by [Mason et al](#) identified six studies relevant to barriers to accessing physical health services.

- Patient-provider communication. Five studies highlighted communication as a barrier; difficulties included registration, communication with the GP, and providers not adopting the patient's preferred mode of communication.
- Executive functioning and planning difficulties. Several studies described individual-level factors related to the autistic person's level of information processing and memory or ability to carry out and plan complex and day-to-day tasks (e.g., taking medication, remembering to prepare for and attend an appointment).
- Sensory sensitivities. Five studies reported different sensory sensitivities as barriers, including waiting room environment, unpredictability (of sensory environment and waiting times), and travelling to the appointment.

### 11.2 Published academic literature- primary sources.

These barriers and facilitators dovetail with categories of different reasonable adjustments (and their importance) reported by autistic adults in [two large cross-sectional UK surveys](#).

Three themes were identified concerning necessary reasonable adjustments:

- Sensory environment.
- Clinical and service context.
- Clinician knowledge and communication.

Survey findings indicate that reasonable adjustments were perceived as necessary in supporting healthcare access, but these adjustments are seldom offered as **69%** of autistic adults were not provided mental health service adjustments, though this was slightly lower for physical health service adjustments (**56%**).

### 11.3 Grey literature

As part of a [national inquiry into access to healthcare for autistic people in England](#), the Westminster Commission on Autism surveyed 863 autistic people, family advocates and professionals, contributing to understanding and informing how to reduce barriers to access. Several key barriers to healthcare access were identified:

- Lack of training for health professionals and lack of accountability. A high proportion (**88%**) stated they felt healthcare professionals did not always understand autism. In 2014, only **29%** of local areas surveyed rated themselves green for having autism training available to all staff (Self-Assessment Framework).

- Sparse data collection and reasonable adjustments. The inquiry notes that a lack of data collection on autism has been seldom collected in England at a general-practice and national level. **Three-quarters** of autistic and parent advocates stated that their doctor does not make any changes or adjustments to meet their needs, which may suggest that health professionals may struggle to identify and make adjustments for autistic people proactively.
- Even when access barriers are surmounted, autistic people may receive poorer healthcare services than those without autism. Around **74%** of autistic parents and professionals surveyed said they felt autistic people receive 'worse' or 'much worse' healthcare than non-autistic people.

## 11.4 Adult mental health services

[A UK-based cross-sectional mixed-method study](#) examined the experiences of autistic young adults between 16 and 25 years of age living with mental health and accessing mental health services, using a community-based participatory research approach with an online survey and in-depth interviews. Key survey findings include:

- While a high proportion (**90.1%**) indicated having sought help from mental health services previously, comparatively fewer suggested that this support was 'extremely' (**13.7%**) or 'very useful' (**23.2%**).
- **Around a quarter** of respondents felt comfortable disclosing or discussing their mental health issues with professionals (**23.5%** felt 'very' or 'extremely' comfortable admitting).

Findings from in-depth qualitative interviews highlight several common themes relating to access and mental health services:

- **Stigma:** Experiencing stigma related to mental health concerns was a major barrier to seeking help, particularly for psychosis or personality disorder-related diagnoses. The stigma around mental health from family members was also reported; respondents felt it was important for clinicians and professionals to address issues such as stigma.
- **Barriers to accessing mental health services:** Several barriers were reported as prominent, including lack of available services for both autism and mental health needs; mental health problems being deemed "[not] severe enough for support"; lengthy waiting times for access; mental health services not being tailored to autism; and poor transition to adult services ("*you hit 18 and all your services just go "poof" and just disappear.*").
- **Quality of care:** The authors report that "*Overall, interviewees were generally unhappy about the standard of the services they accessed: 'I wasn't very happy with any way that my mental health was handled my whole entire life really.'*" - reflecting that some interviewees reported a pressure to show gratitude for support they felt did not go far enough: "*I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel that that was more than I deserved.*"

### **11.4.1 Grey literature**

Several quotes from this briefing highlight the interaction between the increased burden of mental health difficulties in autistic adults and systemic barriers to accessing both timely and sufficient mental health support.

## **11.5 Children and young people’s mental health services**

### **11.5.1 Grey literature**

Autistica has [produced a resource outlining key findings from recent research concerning autistic children and young people’s mental health](#). Many themes highlighted echo Autistica’s briefing on adult mental health, outlining the high burden of mental health conditions in autistic children and systemic challenges in accessing timely and appropriate support.



## 12 Local and National Services

The Local Offers in Northamptonshire can be found by clicking [here for North Northamptonshire](#) and [here for West Northamptonshire](#).

Integrated Care Northamptonshire have a [directory of health and care services](#).

[En-Fold](#) is a local information hub offering direct services and an autism online web resource for information, services, and support within Northamptonshire. The National Autistic Society also has a [service directory](#).

Northamptonshire Healthcare NHS Foundation Trust (NHFT) have a [Children and Young People ADHD and ASC service](#) and an [Adult ADHD, Autism and Tourette's](#) Team within their Mental Health, Learning Disability and Specialty Services department.

NHS England has a webpage of [useful autism resources and training](#).

[Autism Central](#) provide resources, events and one-to-one support for family members and carers of children and adults with autism.

[Neurodiverse Connection](#) is a Community Interest Company (CIC) created to improve support and outcomes for neurodivergent people. Neurodiverse Connection has also recently launched a [black and autistic support group](#).

## 13 Quality and outcomes

NHS Digital published '[Autism Statistics](#)' in November 2019. Data for Northamptonshire Healthcare NHS Foundation Trust (NHFT) is incomplete. Still, we can see here that in quarter 3 of 2018/19, the average waiting time for a first appointment for suspected autism patients was ten weeks compared to a national average of **48**.

SystemOne, the NHS's electronic patient record system, can record autism. The autistic community chose the green letter A as the icon on this system to record an autism diagnosis. Registering autism allows the NHS to plan their service provision, recognise and improve the experience for autistic people and allow NHS staff to identify patients and service users as autistic and adapt accordingly.

This system links with a 'Reasonable Adjustment' dialogue box template that NHFT have worked with NHSE/I to develop, where individual instructions can be recorded to allow the authority to create highly individualised bespoke adjustments.

### 13.1 Reasons for poor mental health in autistic people

- Communication differences not being understood.
- Unhelpful support.
- Sensory differences.
- Negative sense of self.
- Lack of understanding in society.
- Trauma.
- Not being listened to and not being believed.
- Protective factors.
- Understanding self.
- Listened to and accepted.
- Trusting relationships.
- Understanding how others can support.
- Environmental factors.

[The Autism Act 10 Years On](#) document, which informed [the National Strategy for autistic children, Young People, and Adults: 2021 to 2026](#), reported that only **32%** of autistic adults rated mental health professionals' understanding of autism as good or very good. Only **10%** of autistic adults said that social workers had a good sense of autism.

### 13.2 Bullying

[Autistic children are more likely to experience bullying](#), and both [children](#) and [adults](#) with autism are at heightened risk of post-traumatic stress disorder as a result of bullying and other maltreatment and abuse.

### 13.3 Employment

[The employment rate for working-age adults with autism](#) between July 2020 and June 2021 was **29%**. In the six months preceding this, January to June 2020, the rate was **22%**. The rate for the [whole working-age population](#) has been between **72%** and **76.6%** over the last decade.

The employment rates for working-age males with autism were **21.2%** between January and June 2020 and **30.4%** between July 2020 and June 2021. The employment rate for working-age females with autism was **22.8%** between January and June 2020 and **25%** between July 2020 and June 2021.

Autism is not included separately in the data publications before January 2020.

### 13.4 Life expectancy

Autistic people die on average [16 years earlier than the general population due to a multitude of medical conditions](#).

### 13.5 Access to healthcare

Autistic adults experience [significant disparity in healthcare](#), relating to issues including verbal communication skills, sensory sensitivities, challenges with body awareness, slow processing speed, atypical non-verbal communication, and difficulties with organisation.

Tackling health inequalities for autistic individuals is [a national priority](#), with a [training programme on autism for health and care staff made statutory](#).

Alternative paradigms than the medical model, such [Burchardt in 2004](#), are gaining traction, advocating difference rather than impairment ([Mac Cárthaigh, 2020](#); [O'Dell et al. 2016](#)) and the importance of [relationships and quality of life](#).

## 14 Evidence of what works.

### 14.1 Current policy, legislation and guidance

#### 14.1.1 NHS Long Term Plan (2019)

The [NHS Long Term Plan](#) outlines six priority areas of action (and associated actions) to improve the health, longevity, and quality of life of autistic people and people with learning disabilities. Owing to this review remit, this overview focuses on autistic people:

- Enhance community-based support for autistic people, moving care into the community.
- Ensure all NHS services provide a good standard of care and treatment for autistic people and their families.
- Increase investment in intensive, crisis, and community forensic services for autistic people.
- Reducing waiting times for specialist services.
- Reducing health inequalities.
- Improving understanding of autism across the whole NHS and working to improve the health and wellbeing of autistic people.

Since the publication of the Long-Term Plan, the NHSE/I national autism team has been established to oversee the delivery of the commitments set out, aiming to achieve a clearer focus on autistic children, young people and their families.

Specific areas of focus include:

- Reducing waiting times and increasing the quality of autism diagnostic pathways (assessment waiting times; pre-and-post support).
- Develop and pilot annual health checks.
- Ensuring health services put reasonable adjustments in place for autistic people.
- Expanding programmes which aim to reduce and stop the overuse of psychotropic medications in autistic people.
- Working with primary care partners to expand sight, hearing and dental checks to autistic children and young people in residential settings.
- Helping autistic people with complex needs to access personal health budgets and ensuring access to a designated key worker.
- Working with local service providers to reduce avoidable inpatient admissions and plan high-quality person-centred inpatient services that may be accessed as close to home as possible.
- Increasing awareness of the importance of employing autistic people.

### 14.1.2 Learning Disability Mortality Review (LeDeR/ learning from lives and deaths)

Starting in 2015, the [Learning Disability Mortality Review \(LeDeR, or learning from lives and deaths, as it is now known\)](#) is a formal process for reviewing the lives of individuals aged 4 and over with learning disabilities who have died.

Reviews such as these are conducted to understand the health and care services the person who died has received throughout their life. And to inform how healthcare services can be improved to address health inequities and prevent further early deaths. Clinical Commissioning Groups (CCGs) currently hold responsibility for conducting these reviews.

One of the most notable changes is including autistic people in these reviews.

The focus of planned changes to LeDeR governance and processes is to ensure that local health and care systems act upon the findings of such reviews.

For example, NHS England notes that from September 2021, LeDeR will be incorporated into quality reporting arrangements for local ICSs. This mechanism for accountability is intended to improve local learning from these reviews, leading to clear steps for how this learning is translated into tangible service improvements for autistic people.

### 14.1.3 Annual health checks for autistic people

Annual health checks were previously offered to people with learning disabilities or people with learning disabilities and autism, but not to autistic people without a learning disability. [This is despite this group's higher burden of health problems than the general population.](#)

Based on this, one of the key commitments of the [NHS Long Term Plan \(2019\)](#) is to pilot annual health checks for autistic people and extend this more widely if successful. However, there needs to be more information available about what this might entail. The degree to which existing screening tools or areas of the learning disability annual health checks might be adapted is also unclear.

Relevant national guidance for population screening of autistic people and people with learning disabilities has recently been published by [Public Health England](#) in 2021, and [research funded by Autistica](#) (in collaboration with academic partners and NHS England) to design and test such health checks is due to enter its third phase in Autumn 2021. It culminates in a randomised controlled trial to understand the feasibility, acceptability, and effectiveness of health checks for autistic people.

Autistica outlines [several recommendations](#) for action regarding annual health checks, including:

- Integrate autism health checks into CQC inspections for general practices (assessing how prepared local practices are to deliver this).
- Regulatory organisations should collaborate with primary care IT system providers to ensure GPs can access relevant information they need to invite individuals for

annual health checks; this might also ensure that appropriate data is accessible to the individual and that it becomes part of the health record.

- Regulatory organisations, health education providers and Royal Colleges should collaborate to understand how clinicians in primary care might be supported and incentivised to offer annual health checks for autistic people.
- Health education providers and Royal Colleges should come together to develop ways of recognising professionals who have developed specialist knowledge and expertise in the health of neurodivergent people (this might include accreditation of a General Practitioner with Extended Role).
- To improve inconsistent coding of autism diagnoses across GP records, regulatory organisations should collaborate with Royal Colleges and autistic community stakeholders to simplify clinical coding for autism diagnoses and audit local records.

## 14.2 Policy Overview

The focus of national policy related to autism has been [fairly consistent across the last decade](#) with several priority areas related to:

- Increasing societal and professional understanding of autism.
- Developing consistent local diagnostic and wider support pathways.
- Developing the local and national governance required for policy implementation and monitoring.
- Moving care from hospital to community settings.
- Reducing inequities in health outcomes and access to services.
- Improving the consistency of local and national data collection.

The most recent national strategy, which extends the provision of previous policies to children and young people, states three core enablers related to improving research and innovation, improving data collection, and reporting and strengthening governance, leadership, and accountability.

## 14.3 Learning from lives and deaths and annual health checks

The inclusion of autistic people in learning from mortality reviews and the possible provision of yearly health checks for autistic people are [potentially positive developments](#) which [may reduce health inequities](#). Evidence and guidance for local systems to anticipate how they might respond to these priorities is yet forthcoming.

Policy recommendations

Recommendations from [national sources](#) and [other relevant organisations](#) were synthesised across the following topic areas:

- Understanding, training and awareness, Governance leadership and accountability enhancing service provision and understanding autistic peoples' journey through services.

- Access to diagnosis and the diagnostic process, gender disparities, social care, and mental health.

This review identified a major gap in the existing evidence concerning autistic older adults, as reportedly, the literature on autistic adults has focussed on younger adults and those approaching middle age. Specifically, only a handful of papers identified mentioned autism in older adulthood, [such as this from Heriot-Watt University](#).

## 14.4 Criminal Justice

Autistic people are [overrepresented](#) but are [not more likely to offend](#).

## 14.5 Tackling Health and Care inequalities for autistic people

Autistic people die on average [16 years earlier than the general population](#).

## 14.6 Social Care

**71%** of [autistic adult survey respondents](#) from across England said they had unmet social care needs.

## 14.7 Suicide

Over the last seven years, the proportion of suicides where autism is recorded in Northamptonshire is a little over **0.1%**. However, around **14%** of cases don't have a record of whether the individual was autistic or not, so that figure could be much higher. [Reports](#) that adults with autism are **nine times more likely** to die by suicide than the general population, and children with autism are **28 times more likely** to contemplate suicide.

A paper [published by Autistica by Sue Willgoss](#), Advisor for Suicide Prevention with Lived Experience, Norfolk and Suffolk NHS Foundation Trust Founder #LiftLoudForDanny, quotes some startling statistics:

- Suicide is the second leading cause of death for autistic people.
- Average life expectancy for autistic people is just **54 years old**.
- Up to **66%** of autistic adults have considered suicide.
- Suicide attempts tend to be more aggressive and lethal.
- One study showed that **15%** of autistic children had suicidal thoughts compared to **0.5%** of typically developing children.
- In the 86 days leading up to the first Lockdown and up to the 56 days after, **a quarter** of young people who died by suicide were autistic or had ADHD.
- Autistic people make up approximately **1%** of the population but **11%** of suicides.



The report includes recommendations and community priorities.

A [Research](#) (INSAR) provides further statistics relating to suicide and autism:

- The risk of death by suicide is even greater for autistic people without intellectual disability.
- It is also greater among autistic women, who are **13 times more likely** than non-autistic women to die by suicide.

This report contains the same recommendations and priorities as the Autistica paper.

A further report titled '[Personal tragedies, public crisis](#)' looks further into the causes of premature mortality, including suicide, in the autistic population.

## 14.8 Mental Health Inpatients

Currently, [autistic people have a shorter life expectancy](#) than neurotypical people. Autistic adults experience a [significant disparity in health care](#) and are more likely to develop mental ill health but [less likely than non-autistic people to get support](#).

There is an [increased incidence of autistic adults in mental health wards](#) compared to in the community.

## 14.9 Homelessness

[Emerging research](#) suggests that autistic people are disproportionately represented in homeless populations.

## 14.10 Training

Although it is promising in tackling explicit bias against autism, it has not been shown to reduce implicit bias.

The Health and Care Act 2022 required that all CQC registered service providers ensure their staff have training on learning disability and autism that is appropriate to their role. The [Oliver McGowan Mandatory Training on Learning Disability and Autism](#) is the Government's preferred and recommended training for health and social care staff to undertake.

## 15 Recommendations

Where possible, appropriate and legal consider recording data relating to autism for service users, customers and patients. For example, whether an individual is autistic and what the outcomes were for that individual.

Make reasonable adjustments to accommodate autistic people when accessing information, services, locations or employment.

Adopt the recommendations from Autistica's '[Suicide and Autism: A National Crisis](#)' and their [action briefing on health checks](#).

Adopt the synthesised recommendations referred to [earlier in this paper](#) and repeated here for convenience –

- Understanding, training and awareness, Governance leadership and accountability enhancing service provision and understanding autistic peoples' journey through services.
- Access to diagnosis and the diagnostic process, gender disparities, social care, and mental health.

Embed and monitor Autism into Equality Impact Assessments.

Further research should use secondary and/or local datasets to understand the most common causes of hospitalisation, criminalisation, employment and other adverse health or service utilisation outcomes.

Alongside quantitative data, ensure lived experience knowledge, participation and engagement is embedded into reports and reviews to provide qualitative information.

Move away from [reliance on medical models](#).

The Autism Strategy Action Plan, a constantly evolving project, should reflect the work and the detail undertaken to produce this list of recommendations.

[Nothing about us without us.](#)

