

National
Autistic
Society

A constant fight

The reality of autistic people's
struggle for support across
health and social care, education,
employment and mental health

Contents

About autism and us	3
Executive summary	4
Key statistics	6
Introduction	8
Diagnosis	10
Education	15
Employment	19
Mental health	23
Health inequalities	30
Endnotes	36

About autism

Autism is a lifelong disability which affects how people communicate and interact with the world. There are over 700,000 autistic adults and children in the UK. Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

About us

The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people. We transform lives by providing support, information and practical advice for the over 700,000 autistic adults and children in the UK, as well as three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face. We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws.

www.autism.org.uk

Executive summary



Autism needs to be a policy priority for the new Government. As this report sets out, autistic people face some of the greatest inequalities in society across health and social care, education, employment and mental health. Fundamentally, autistic people's experiences represent a key test of public policy: if you can make the system work for autistic people, it is likely to work better for everybody.

The autism assessment and diagnosis process underpins all other policies and support available for autistic people. However, services have not kept up with increased demand. Most autistic people receive little to no support before or after diagnosis and are ultimately left to fend for themselves in overstretched, inaccessible public services.

As of September 2024, 204,876 people were waiting for an autism assessment in England, latest NHS data has revealed, and 89.4% (183,200) have been waiting longer than the recommended 13 weeks.¹ Many people are waiting many months and even years for an assessment.

Immediate ringfenced funding, alongside a long-term funding commitment for autism assessments and support, would stabilise the national model in the short term and lay the foundations for innovation, testing and evolution.

There are 230,000 autistic pupils in England,² and only 26% of them feel happy at school.

We know that autistic students and their families are not getting the support they need to thrive at school – 74% of parents or carers say that their child's school place does not meet their needs, and 26% of families have waited more than three years for their child to access support.³

Local authorities do not have the capacity or funding to support families with Education, Health and Care Plan (EHCP) implementation. Because of this, families must increasingly turn to the special educational needs and disability (SEND) tribunal to fight for their child's rights. 98% of SEND tribunal cases were resolved in favour of parents,⁴ demonstrating that the issue is not the legitimacy of requests for support, but barriers to implementation.

Alongside providing the needed funding for the broken SEND system, we need to see: autism training made mandatory for all school staff; improved commissioning of school places to address the growing problem of a lack of appropriate school places for autistic students; and joined-up work between schools, local authorities and health and social care services.

Only three in ten autistic people are in work.⁵ A lack of autism understanding, experiences of discrimination and a lack of support and adjustments within employment all play a fundamental role in autistic people facing significant barriers in employment.

Our goal is to halve the autism employment gap and have 55% of all autistic adults working by 2030. Research by Pro Bono Economics suggests that doubling the autism employment rate would generate benefits of up to £1.5 billion each year, adding 100,000 extra workers to the labour force and increasing their economic contributions significantly.⁶

70-80% of autistic people suffer with a mental health problem during their lives. Yet, services are rejecting referrals for autistic people and failing to take responsibility. This leads to autistic people being bounced around between services. In many local areas, there is no alternative if a service cannot provide support.

The only way out of this crisis is to invest in a mental health workforce and community services that work for autistic people. Whilst there are many small changes that can be made to improve mental health services, additional funding is needed to develop, trial and maintain better service models. This needs to be done alongside the long-needed legislative reform to the *Mental Health Act*.

Autistic people experience some of the greatest health inequalities in society. Autistic people are more likely to experience both chronic physical health conditions and mental health conditions. Despite this, getting access to the right healthcare support, from routine GP appointments to specialist advice and treatment for co-occurring chronic conditions, can be a fraught process.

The Government must make sure that autistic people are fully involved and included in the NHS 10-year plan. The healthcare barriers currently experienced by autistic people are not insurmountable and should be addressed urgently and effectively or autistic people will continue to experience unjustifiable and life-limiting health inequalities.

Autistic people are bearing the brunt of broken support systems in education, employment, health and mental health. No one understands this better than autistic people themselves. By listening to autistic people on the issues they are facing across all these areas and identifying solutions to create a society that works for all autistic people, we can improve services and support across the board.

Key statistics



80% of autistic adults report difficulty visiting a GP.⁷



Autistic people are **over three times** more likely to say they frequently leave a healthcare appointment feeling as though they did not receive any help at all.⁸



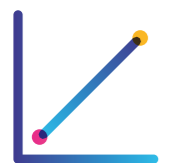
Autistic people die around **six years earlier** than the general population, and autistic people who also have a learning disability die up to 15 years earlier.⁹



There are **1,410** autistic people in psychiatric hospitals in England.¹⁰



The number of autistic people without a learning disability detained in mental health hospitals has increased by **122%** since 2015.¹¹



As of September 2024, **204,876** people were waiting for an autism assessment in England. This is a **25% increase** in just one year.¹²



Only **14%** of autistic adults said there were enough mental health services in their area to meet their needs.¹³



Only **26%** of autistic pupils say they feel happy at school.¹⁴



7 in 10 parents of autistic children say their child's school place doesn't meet their needs.¹⁵



There were **14,000 appeals** to the SEND tribunal in the 2022/23 academic year. This was an **increase of 24%** on the previous year.¹⁶



98% of SEND tribunal cases were resolved in favour of parents, demonstrating that the issue is not the legitimacy of requests for support, but barriers to implementation.¹⁷



Only **3 in 10** autistic adults are in work, compared to 52.6% of disabled people - the lowest for any disability.¹⁸

Introduction



Autism needs to be a policy priority for the new Government. Although autistic people represent more than 1% of the country's population,¹⁹ as this report sets out, autistic people face some of the greatest inequalities in society across health and social care, education, employment and mental health. Fundamentally, autistic people's experiences represent a key test of public policy: if you can make the system work for autistic people, it is likely to work better for everybody.

On this basis, prioritising autism is key to delivering the new Government's missions, particularly kickstarting economic growth, breaking down barriers to opportunity and building an NHS fit for the future.

No one understands better the issues facing autistic people in this country and what changes will make a big difference than autistic people. This is why this report is written fully by autistic National Autistic Society staff and includes powerful case studies provided by autistic people or close family members.

Shifting the health and social care system to a focus on prevention and early assessment of need would make the single biggest difference for autistic people. Avoidable deaths remain far too frequent. 77% of autistic adults reach crisis point while waiting for the right community care to be provided²⁰ and many wait years, rather than weeks, for an autism assessment. Autistic young people also need to be able to access support throughout their time in education and in the community.

Services far too often fail to work together across disciplines. The cost of failure of services to understand and support autistic people is tragically exemplified by the case of Jen Bridges-Chalkley, as described on the next page.

Content warning: Jen's story is about suicide and readers will find it upsetting.

Jen's story, as told by her mother Sharren

"Jennifer, or Jen as she preferred to be known, was born in February 2004. Her personality shone from a young age - inquisitive, caring, often mischievous! During her early days at school, it became clear that Jen was struggling to fit in with the 'norm'. Jen loved being outdoors, in nature and with animals; she also loved swimming and free diving.

Primary school was a positive experience for Jen where she was in a nurturing environment. Secondary school was very different with more people, larger academic load and social pressures to 'fit in'.

Jen received an ADHD diagnosis and an autism diagnosis by age 11. I took Jen to the GP aged five with suspicions of ADHD. It took a serious incident at primary school for Jen's 'quirks' to be properly acknowledged, only then was Jen finally accepted on a diagnosis pathway.

Jen's schools didn't seem to fully understand the EHCP process, nor how important having an EHCP is for a child both in and outside of school. Jen didn't get an EHCP until she was 15, five years after her first diagnosis, and over a year after her first disclosing a suicide attempt.

I applied for the EHCP as soon as I was made aware that parents could apply, without going through the school. This is one of multiple communication failures by education and mental health

services - had I been aware I could apply, this would have been done before Jen reached crisis.

Jen began self-harming at age 11. A GP referred us to Child and Adolescent Mental Health Services (CAMHS), but Jen's mental health "wasn't bad enough" for support. Three years later, after Jen disclosed an intention to end her life, we had our first interaction with CAMHS. Jen was put on a waiting list. She never managed to get off the list before being discharged by CAMHS as "she seemed okay". This was in spite of multiple admissions to hospital for suicidal intentions and referrals from her paediatric team.

The evening before Jen's final, devastatingly successful attempt on her life, I asked her if she wanted to go to the hospital for help. Her reply was "No Mummy, there's no point, they never have and they won't this time".

On 12 October 2021, Jen died by suicide aged 17.

The inquest into Jen's death concluded that CAMHS' failure to assess, diagnose and treat Jen, the failure of Surrey County Council to ensure her EHCP reflected her mental health needs and the multi-agency systemic failures to work together contributed to Jen's death."



Diagnosis



The number of people being diagnosed as autistic has risen greatly in the past few years, because of an increased understanding about autism.²¹ People seeking and receiving an autism diagnosis is a good thing. It means more people have a better understanding of themselves and the support they and their families need. And while it shouldn't be the case, diagnosis is often needed to get support in education and employment.

In the past, it was assumed that autistic people were overwhelmingly men and boys, but anybody can be autistic regardless of gender, race or class. More people, including those from marginalised groups, are seeking a diagnosis than ever before; however, they face additional inequalities and barriers to getting a diagnosis.

The autism assessment and diagnosis process underpins all other policies and support available for autistic people. However, services have not kept up with increased demand. Most autistic people receive little to no support before or after diagnosis and are ultimately left to fend for themselves in overstretched, inaccessible public services.

Autistic people are expected to justify their diagnosis throughout their lives in a way that is not expected for many other conditions. But a diagnosis can provide important insights that are life-changing, and sometimes even lifesaving.

But getting a diagnosis is difficult and people face a long, bureaucratic and stressful process to get diagnosis and support. The diagnosis process can involve hours of recounting traumatic experiences and focusing on perceived deficits, as well as long waits for the actual assessment. Black and global majority ethnic autistic people and their families face significant additional barriers and difficulties in accessing a diagnostic assessment, receiving a diagnosis and getting support.²²

Lauren's story

"As a Black woman, having been diagnosed as autistic later in life, my journey highlights the pervasive barriers that marginalised groups face within the UK's health and social care systems. For years, my behaviour and experiences were disbelieved and misinterpreted, resulting in misdiagnosis, missed opportunities for support and health inequalities that significantly impacted my quality of life. My autistic traits were often dismissed or pathologised, with professionals attributing my struggles to other factors rather than recognising them as part of a neurodevelopmental condition. Autism, especially in Black women, is still not widely understood or acknowledged, leading to years of misunderstanding and structural neglect.

The intersections of my identity, as a Black woman and an autistic person, intensified these challenges. I was and still am often overlooked, with my differences perceived as behaviours to be 'managed' rather than signs to be explored for possible neurodivergence. The lack of awareness around autism within minority communities, compounded by systemic biases, meant that accessing a correct diagnosis was a long and arduous journey, filled with unnecessary suffering.

I encountered assumptions and prejudice at every stage, reinforcing the reality that structural inequalities, rather than personal failures, have perpetuated my struggles.

Being diagnosed as autistic was transformative. For the first time, I felt truly seen and validated in my experiences. The correct diagnosis has provided a framework that better aligns with my needs and has empowered me to advocate for myself and others alike, more effectively. It's also reduced some of the stigma and confusion I carried, helping me to understand my strengths and limitations in a way that I can communicate to others. This diagnosis didn't just affirm my identity, it has facilitated access to more appropriate support, helping me live a life that is more fulfilling and authentic.

By sharing these experiences, I hope to underscore the need for MPs to address the complex, intersectional barriers facing autistic people, particularly those from global majority backgrounds. An inclusive and nuanced approach to policy change is essential to ensure that everyone, regardless of race or gender, has equitable access to diagnosis, understanding and support."



Current situation



As of September 2024, **204,876** people were waiting for an autism assessment in England, latest NHS data has revealed. This is a **25% increase** in the number of people waiting in just one year.²³



NICE (National Institute for Health and Care Excellence) guidance states that no one should wait longer than 13 weeks. **89.4% (183,200)** have been waiting longer than the recommended 13 weeks.²⁴



If waiting lists continue to grow at this rate, by autumn 2025, there will be over **256,095** people waiting for an autism assessment.

The NHS is chronically underfunded, and autism services across the country lack the resources and workforce necessary to meet this demand. Clinicians are facing an impossible task.

NHS England's (NHSE's) framework and operational guidance for all-age autism assessment pathways provides an outline for the standardised process that all NHS providers should be following to deliver timely and effective assessments.²⁵

This is an important first step. However, it is clear both from feedback from Integrated Care Boards (ICBs) and from the actions some ICBs have taken to try

and ration access to an assessment,²⁶ that without substantial additional investment or reform, the guidance is impossible to implement.

A recent report from Children's Commissioner Rachel de Souza: *Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions*, highlights the extent of the crisis, particularly for children and young people. It uses NHSE data on diagnosis which is not publicly available (from the Mental Health Service and Community Service Data Sets), as well as qualitative interviews.²⁷

The report provides further strong evidence that diagnosis services are not adequately resourced to keep pace with increasing demand, and as a consequence: "we are robbing children of their childhood and potential". For autism, the average wait time in community health services is two years and two months, and whilst shorter in mental health services, the wait for support is still as long as one year and five months.

Interviews undertaken for the Children's Commissioner's report found:

- The system is working against itself as children are pushed to get a diagnosis to receive SEND support, whereas it should be decided simply by looking at the child's individual needs. Children wait years for a diagnosis with no support at all put in place during the waiting period.

- Children are still receiving the wrong referral or being put on the wrong assessment pathway.
- There is no workforce to conduct follow-up support - children and parents are only being given a list of websites to find more information.
- Children with neurodevelopmental conditions face a number of health inequalities, based on their socioeconomic background, where they live, their gender and ethnicity.
- Families who can afford to and choose to pay privately for neurodevelopmental disorder assessment and support can access help much quicker than families who cannot afford to.

What needs to change

With the extent of the crisis, urgent ringfenced funding is needed. The situation cannot be solved immediately, but planning must start now to make sure we are not in this situation for decades to come. The Government must think long term – a lack of assessment and support leads to avoidable crisis. Aside from the devastating personal costs, the continued costs of rising inpatient detention and high unemployment of autistic people mean inaction is costly.

A long-term funding commitment for autism assessments and support would stabilise the national model in the short term and lay the foundations for innovation, testing and evolution. Reflecting estimates made by NHSE, the National Autistic Society proposes an investment of £1.3 billion over the next 15 years to evolve the assessment process.

The investment would:

- take immediate action to address the gulf between current workforce and demand
- expand the multi-disciplinary workforce for autism assessment through recruitment, training and deployment, allowing more need to be met and the waiting list to be shortened over time. The investment may need to be front-loaded to enable this
- develop and test innovative new models of identification and support for autistic people by driving forward research
- ensure services in the community are sufficiently resourced and equipped to support everyone based on individual needs.



Education



There are 230,000 autistic pupils in England.²⁸ Yet, our research found only 26% of autistic pupils feel happy at school.²⁹ We know that autistic students and their families are not getting the support they need to thrive at school – 74% of parents or carers told us that their child's school place does not meet their needs, and 26% of families waited more than three years for their child to get support.³⁰

A strong education is the best possible start in life and, currently, autistic pupils are being left behind.

Some autistic children and young people are being denied their fundamental right to education, unable to go to a school that meets their needs, supports their growth and development and where they feel safe and supported.

Current situation

Councils are struggling to manage rising costs associated with the provision of Special Educational Needs (SEN) support. For example, spending on SEND transport is set to hit £1.4 billion across England in 2024-25, a 95% rise from the £728 million that was spent in 2018-19.³¹ Concerningly, the increased spending has not led to improvement in the support available or better outcomes.

Nationwide action is needed for autistic young people to have the opportunity to engage with mainstream education and for those who require a higher level of support to receive it.

Councils do not have the capacity or funding to support families with implementing Education, Health and Care Plans (EHCP). Because of this, families must increasingly turn to the SEND tribunal to fight for their child's rights.



There were **14,000** appeals to the SEND tribunal in the 2022-23 academic year. This was an increase of **24%** on the previous year.³²



£60 million of public money was wasted sending families to tribunal in 2021-22.³³



98% of SEND tribunal cases were resolved in favour of parents, demonstrating that the issue is not the legitimacy of requests for support, but barriers to implementation.³⁴



What a tribunal may rule as necessary for a child or young person **may not be possible** for a council to implement because they don't have the money.

The most frequent reason for an exclusion is 'persistent disruptive behaviour'. This is often a sign that a child's needs are not being met. Schools must do better to understand the needs of autistic pupils if these critical attendance issues are to be addressed. Autistic pupils who are Black or of the global majority, especially those who are eligible for free school meals, are even more likely than other pupils to experience exclusions.³⁸

Our research found that without appropriate teacher training, autistic children are twice as likely to be excluded from school.

Also, while 87% of teachers felt confident supporting autistic students in the classroom, over 70% of autistic pupils told us that their teachers didn't understand enough about autism. Only 39% of teachers surveyed had received more than half a day's autism training, and for secondary school teachers, this falls to just 14%.³⁹

Autistic pupils struggle disproportionately with attendance and attainment.



The persistent absence rate for all pupils is **20.7%**, compared to **31.1%** of autistic pupils.³⁶



Autistic pupils are more than **twice as likely** to be excluded as non-SEND students.³⁷

Tulsi's story

"My name is Tulsi, I'm 20 and a first-year university student studying for a creative degree. I have been diagnosed with autism, attention deficit disorder, learning difficulties, dyspraxia and anxiety.

My teachers noticed that I was falling behind academically during my early years. This led to an educational psychologist assessment. In my later years at primary school, I struggled to maintain friendships. I felt left out and lonely most of the time. At this stage, I was not diagnosed with autism. My difficulties with social communication interaction were not identified as a concern. If this had been picked up earlier, I might have been diagnosed sooner, leading to more appropriate interventions to support me.

Halfway through my first year in secondary school, I was granted an EHCP. This allowed us to choose a more appropriate school to meet my needs. We chose a mainstream school with an attached SEN unit. This base gave me a safe space to go to when I felt insecure or needed support. It also allowed me to integrate into mainstream school. The best thing about my secondary school experience was not feeling excluded from school events and opportunities. I was chosen to be a student learning consultant and given several awards.

My EHCP also meant I was in classes with a teaching assistant and the lesson plan was broken down to make it more accessible.

I was diagnosed with autism in my first year of secondary school. However, this diagnosis was not well-explained or supported by professionals. My EHCP had recommendations to help with my difficulties with social communication skills, but there wasn't enough resource, awareness or teacher training for successful interventions. I made a few good friends, but I struggled to interact with my peers. This led my parents to pay for a private assessment and referral to a specialist, confirming a diagnosis of autism and ADD at the end of my secondary school years. I wish that more help was available sooner as I felt I missed out on the social aspect of being with friends.

Starting university has been a completely different experience. Applying for Disabled Students' Allowance (DSA) was simpler, and the assessment was more meaningful and tailored to my needs. Through the DSA, I have received technical support and am now awaiting specialist study skills and mentor support. My journey has been full of challenges, but I am very proud of where I am today."



What needs to change

75% of autistic pupils are educated in mainstream schools.⁴⁰ We hear frequently from young people that their schools do not meet their needs, and many autistic young people struggle with accessing a suitable school place.

To make mainstream schooling more accessible for autistic children and young people, there needs to be:

- improved teacher understanding of autism
- regular access to quiet spaces
- classrooms that accommodate sensory needs
- improved commissioning of school places to address the growing problem of a lack of appropriate school places for autistic students.

Improving mainstream provision could reduce the need for some autistic children and young people to need reasonable adjustments through an EHCP. Creating more accommodating and accessible mainstream schools could reduce exclusions and emotionally-based school avoidance (EBSA) as well as reducing the need for families to rely on tribunals to get their child support.

Funding mainstream improvements is also key to addressing the SEND budget crisis. This should include:

- funding for all school staff training on autism
- increasing funding for mainstream school places
- investing in capital improvements to create classrooms and quiet spaces that suit autistic children's needs
- ensuring that provisions such as mental health support and employment support are tailored to meet the needs of autistic pupils.

The commitment, in the 2024 autumn Budget, of an additional £1 billion for SEN was welcome but much of this money will be used to relieve council debts instead of implementing SEN support, so will do little in real terms to improve support to autistic young people. Further investment in SEND is needed to make sure that councils can act when tribunals find that support should be in place. Investment could also provide the funds to make sure that autistic children have their needs met without needing to go to tribunal.

To prevent students being misunderstood, punished and sometimes excluded from school, and the impact this can have on wellbeing, attendance and attainment, training in autism must be made mandatory for all school staff. The 2022 *Health and Care Act* made training in autism and learning disabilities mandatory for all health and social care staff; the same can and must be done in schools, to make sure autistic people are understood by those with responsibility for their learning and wellbeing.

To deliver effective training and ensure best practice, we recommend the delivery of training by The Autism Education Trust (AET), who already work in partnership with the DfE to deliver training to over 100,000 teachers a year.



Employment



Only three in ten autistic people are in work, the lowest of any disability. This shouldn't be the case. Most autistic people can and want to work but face multiple barriers both in finding employment and progressing when in work.

Key barriers to employment include:

- a lack of autism understanding in workplaces
- experiences of discrimination
- a lack of support in implementing or asking for adjustments.

There are barriers at all stages, including:

Getting a job:

- job descriptions and person specifications that are vague or ambiguous
- the social nature of traditional job interviews; for example, meeting and interacting with new people
- ambiguous or unclear interview questions
- open-ended questions, such as 'what are your strengths and weaknesses?' or 'tell me about yourself'
- not being given clear information about what will happen at the interview; for example, the timeframes and structure of the interview
- reading other people's, and managing your own, non-verbal cues and body language.

In employment:

- autistic employees often don't feel confident that employers, managers and colleagues know enough about autism to support them in the workplace
- autistic employees often feel unable to discuss their adjustment needs, and of those who did, over a quarter were refused
- management instructions may be unclear or leave much of the instruction unspoken, resulting in the autistic person not understanding what they're being asked to do
- non-autistic colleagues misinterpreting the communication style or behaviour of the autistic person
- focusing on work instead of socialising can be viewed as unfriendly
- discrimination, negative stereotypes and assumptions being made about autistic employees
- career progression being dependent on highly social activities and interpersonal skills
- sensory overload
- coping with change or disruptions to routine
- additional stress from navigating social situations like office politics, unwritten rules etc.
- noisy working environments
- commuting to work
- ambiguous or non-existent feedback about their performance.

Current situation

Only three in ten autistic adults are in work, compared to 52.6% of disabled people - the lowest for any disability.⁴¹ 77% of unemployed autistic people want to be working. 40% of autistic people in work want to be working more.⁴²

A report by the Work Foundation found 38% of autistic people were in severely insecure work.⁴³ The Office for National Statistics found that autistic employees had the largest pay gap of any group of disabled people in the UK, with their average pay being 33.5% less than that of non-disabled people.⁴⁴

The recently published *Buckland Review of Autism Employment (2024)* suggests that, in total, the autism employment gap costs the UK economy approximately £14.5 billion every year.⁴⁵



What needs to change

Our goal is to halve the autism employment gap and have 55% of all autistic adults working by 2030. Research by Pro Bono Economics suggests that doubling the autism employment rate would generate benefits of up to £1.5 billion each year, adding 100,000 extra workers to the labour force and increasing their economic contributions significantly.⁴⁶

Support for employers will be vital in achieving this goal. Employers are too often unsure of the best ways to support autistic people at work, with nearly 60% of employers telling us they would worry about getting things wrong, and 60% of employers not knowing where to go for advice on employing autistic people.⁴⁷

Employers need to:

- understand autism
- implement reasonable adjustments in recruitment and workplaces
- engage with autistic jobseekers during recruitment
- demonstrate that their workplaces are autism-friendly.

This support could be delivered in several forms:

- employer training
- public campaigns
- sharing good practice in different sectors.

For example, the Buckland Review recommended the Government work with autistic people, autism organisations and employer-facing organisations to create a national campaign aimed at employers, highlighting ways of accommodating autistic employees, success stories and where to find resources.





Moving Forward, NAS Scotland

Ewan, age 25

"In 2023, I was going through a rough period in my life having dropped out of college, unable to find a job and not really knowing what I wanted to do with my future. I was stuck - I wanted to find work and had more than enough ability to actually do the work, but without the knowledge of how to actually find a job or the social skills needed to get past an interview, I was lost. In this period, I was aimless and depressed. Every day felt empty. My dad decided to reach out to the National Autistic Society on my behalf, and I was added to the Moving Forward+ programme, which really helped me overcome the hurdles that were blocking my way to employment. I have since been employed for just over a year as of writing this and having that work has vastly improved my mental health and overall happiness in life."

Stephen (Ewan's father)

"My son's autism means he has always struggled with communication skills and would have been unlikely to be able to attend a regular interview process without the skills and confidence gained through the Moving Forward+ programme. There has been a great improvement in my son's self-confidence as a result of attending the course."

His social skills improved with a basic understanding of 'small talk' and how to strike up a conversation. He also learned about himself and his autism and how to cope better.

The programme identified an area of work he would be good at, and he appears to enjoy working in IT. He certainly doesn't appear anxious when he's going to work, where he would have struggled with that before. My son is now out each day mixing with other people where he would previously not leave the house. He is also managing his money and timekeeping for his job. I can't praise the Moving Forward+ programme enough and have already recommended it to others."

*We have changed the name of the participant and their parent to preserve their anonymity.

Moving Forward is a National Autistic Society Scotland programme that assists autistic young people to build their confidence and resilience before re-engaging with education or moving into positive activity, including employment.

Mental health



Autism is not a mental health condition. However, autistic people are more likely to develop a mental health problem throughout their lifetimes than non-autistic people. The development and worsening of these mental health problems is often preventable.

The reality is mental health services are often not accessible for autistic people.

Autistic people have shared details of multiple barriers, including:

- long waiting times
- a lack of local mental health services
- overstimulating sensory environments
- a lack of research and understanding about the ways that mental health issues may present differently in autistic people
- difficulties with reciprocal communication and building trust within limited numbers of sessions available.

This can lead to sub-standard care or inappropriate and even harmful interventions.

This can have devastating consequences. Without adequate community support, many autistic people are reaching mental health crisis. This can lead to traumatic detentions in psychiatric hospitals which cannot meet their needs. Suicide also remains one of the highest causes of death amongst autistic people.

We want to work with Parliament to build an NHS fit for the future where every autistic person can access the mental health care they deserve. This can only be achieved by recognising the needs of autistic people and involving them at every step.

Current situation

70-80% of autistic people suffer with a mental health problem during their lives.⁴⁸ This rate is likely higher amongst those who are gender diverse.⁴⁹



Our 2020 mental health survey found:

94% of autistic adults report experiencing anxiety - **30%** fall into the severe category.

83% report experiencing depression - half fall into the severe category.

76% reached out for mental health support in the last five years.

82% said getting support took too long.

Only **14%** said there were enough mental health services in their area to meet their needs.⁵⁰

We continue to hear of services rejecting referrals for autistic people or failing to take responsibility. This leads to autistic people being bounced around between services. In many local areas, there is no alternative if a service cannot provide support.

Even when a service is accessed, interventions and therapies are often not adapted for autistic people, and services don't provide the individualised and holistic care needed.

Access can be even harder for Black and global majority ethnic people. Services are often not culturally sensitive, and professionals' perceptions and prejudices can negatively influence the quality of care provided. Negative experiences and discrimination can lead to disengagement from services altogether.

The 2011 Winterbourne View scandal revealed the abuse that autistic people may suffer in mental health hospitals, and there have been several scandals since. Despite this, targets to move autistic people out of mental health hospitals and into the community have been missed.

The 2019 NHS Long Term Plan included a target to halve the number of autistic people and people with a learning disability detained between 2015 and March 2024.⁵¹

This target was not met; whilst some progress has been made for people with a learning disability, the number of autistic people without a learning disability detained has increased by 122%.⁵²

It is widely recognised that mental health hospitals are inappropriate for most autistic people and can be deeply damaging. We continue to hear stories of abuse, overmedication, unnecessary restraint and solitary confinement.



NHS England data shows:

There are **1,410** autistic people in psychiatric hospitals in England.

There are **215** under-18s in inpatient units who are autistic or have a learning disability - **95%** are autistic.

The number of autistic people without a learning disability detained has increased by **122%** since 2015.

The average length of stay is **4.9 years**.

92% are detained under the *Mental Health Act 1983*.

This is a human rights scandal. Many autistic people could have had their needs better met in the community but are instead deprived of their liberty and dignity. In 2019, the Joint Committee on Human Rights concluded that autistic people's human rights are being breached in hospitals, and this may even violate the European Convention on Human Rights (ECHR).⁵³

Community support has seen minimal progress. Autistic people are often discharged from hospital with little support or placed in unsuitable accommodation. This is leading to a high rate of readmissions. In October 2024, 27% of admissions within the month for autistic people without a learning disability were readmissions within a year.⁵⁴

Autistic people are more likely to think about, attempt and die by suicide than the general population. Research suggests that 66% of autistic adults experience suicidal ideation (nine times higher than the general population).⁵⁵ As many as 11% of people who die by suicide in England may be autistic.⁵⁶ Additionally, autistic women are up to four times more likely to make a suicide attempt than autistic men.⁵⁷

Risk-factors include: undiagnosed or late-diagnosed autism, barriers to accessing support, pressures to mask, feelings of not belonging, traumatic experiences and unemployment.



Marsha's story

"I'm Marsha, a Black, late-diagnosed autistic mother to three autistic girls, and the founder of Black SEN Mamas; a charitable organisation that provides mental health intervention and SEND advocacy services for Black mothers raising neurodivergent/disabled children.

As a Black autistic woman, I've experienced systems that often fail to see, hear or understand the unique challenges faced by autistic individuals, particularly those from ethnic minority backgrounds. I'm acutely aware that I often face gender bias, racial discrimination and ableism.

I was well into adulthood and proactively trying to get a diagnosis for my first child before I recognised my own potential neurodivergence. The challenges of navigating a neurodivergent brain in a world that often doesn't understand or accommodate difference have always been a part of my life, but I only gained language for this when I was much older. Growing up, I struggled with sensory overload, social interactions and communication in ways that didn't fit into the typical mould of neurodivergence. For years, I thought there was something 'wrong' with me.

As a Black woman and as an autistic mother, I found myself battling on multiple fronts: explicit racism in the SEND

mother and baby groups, systemic barriers from the local authority and schooling system, lack of understanding about autism from both within and outside of the Black community, and a general dearth of resources specifically tailored to the needs of Black families. All of this whilst trying to navigate caregiver stress and maintain good mental health, so I can ensure my child had a good quality of life, despite societal failings.

I've had to be a constant advocate, not only for my children's needs, but for my own. The emotional and mental load is immense. It is exhausting and often feels like an uphill battle, especially when the very systems I'm trying to engage with are ill-equipped to support Black, autistic families. This is why my organisation prioritises implementing mental health intervention for mothers, as a first port of call. Sadly, much of the work we do is suicide prevention. The decline in the mental health of these parents is a direct result of constantly fighting for the bare minimum in terms of statutory support and watching their children fail to thrive and usually deteriorate, due to the lack of support from the system and from society in general."



Raivyn's story

"I have spent from 2020 to now in CAMHS. In 2021 I came out as trans and was diagnosed with autism privately with the National Autistic Society due to the lengthy NHS waiting lists. My time in the system has been a constant battle as it always feels like I'll never be bad enough for them to intervene - that whatever I do to prove I'm in pain won't get me the help I need. I've been proved right.

As I was a model student, professionals assumed I was 'fine', but I was at rock bottom. A cycle repeated for three years where I got to crisis point, went to hospital, was medically discharged, given a longer safety plan, but ultimately no change was made to my care. Everything felt too much, nothing changed when I asked for help but when I did risky things, CAMHS reacted.

Professionals heard my words but didn't understand or offer support, so I fell further into despondency while professionals labelled me as a high functioning complex case and put me on waiting lists. Riskier cries for help ended in numerous hospital admissions thinking I was beyond saving - all because no one understood me.

Although I had an AuDHD (autism and ADHD) diagnosis, no professionals seemed to take it on board (or my gender) when coordinating my care.

One CAMHS worker told me, "We don't deal with autism".

Nothing was helping and I needed appropriate support; my behaviour escalated in a way I knew would get them to respond, which ended in my admission to a psychiatric hospital.

It was then that the approach shifted to match my AuDHD profile, and they used different therapeutic models to accommodate for my neurodiversity. On the ward, most patients had autism and/or ADHD. During my four-month admission, I was traumatised by physical and verbal assaults from patients, neglect from staff and isolation from friends and family.

From being on track to get ten GCSEs grade 8/9, now I have two GCSEs and I'm only doing five more because of the impact of my mental health on my education. Overall, my psych admission has helped, especially accessing (through the Dynamic Support Register) the key working service that provides essential emotional and practical support. If professionals took the time to look at my case holistically and had more knowledge about what treatments work best for autistic people, I think it would help to restore faith in the system and prevent avoidable hospitalisations."



What needs to change

The only way out of this crisis is to invest in a mental health workforce and community services that work for autistic people.

Whilst there are many small changes that can be made to improve mental health services, additional investment in community services is vital. The recently introduced *Mental Health Bill* cannot be implemented in full, nor can it be effective in achieving better mental health outcomes for autistic people, without significant investment in preventative mental health care.

Funding should support the developing, trialling and maintaining of service models that work for autistic people in the community. Investment in community support, including social care, can also help to speed up hospital discharges and ensure no one is in a mental health hospital any longer than necessary.

Improving workforce retention is also crucial. We continue to hear of professionals misunderstanding the relationship between autism and mental health or failing to put reasonable adjustments in place. This is exacerbated by an overreliance on agency staff. Consistency of staffing helps to build trust, which can lead to better mental health outcomes.

Professionals need better awareness of policies designed to prevent autistic people being hospitalised. This includes the Dynamic Support Register (DSR) and community Care (Education) and Treatment Reviews (C(E)TRs). These policies ensure autistic people who are at risk of hospitalisation are getting the right support in the community and are not 'falling through the gaps'.

We have also heard how the keyworker service for autistic children and young people can be very positive. This must be extended as far as possible.

Professionals must treat autistic people as individuals and not delineate them into different conditions or bounce them around services which are not joined up. This also means identifying therapeutic models that might benefit autistic individuals and understanding how to adapt common therapies to increase efficacy for autistic people.

Mental health reform

The Government introduced the *Mental Health Bill* to Parliament in November 2024. This includes a provision to remove autism from the definition of 'mental health disorder', which would prevent autistic people from being detained in mental health hospitals just because they are autistic.

As the Bill makes its way through Parliament, it must be strengthened to enhance duties to provide adequate support for autistic people in the community; improve review processes and protections for autistic patients; and ensure treatment is always therapeutically beneficial.

Changes to legislation will help end the scandal of autistic people being inappropriately detained in mental health hospitals. However, some autistic people with co-existing mental health conditions may still require hospitalisation.

What needs to change

Many actions from the current Building the Right Support programme, which aims to reduce the number of autistic people and people with a learning disability being hospitalised, have been completed or lapsed. A new action plan must be developed and include a new target aimed at reducing the number of autistic people in mental health hospitals.

Investment in appropriate housing for autistic people is also needed. This can reduce the level of distress caused by wrong sensory environments and is especially important for autistic people being discharged from mental health hospitals.

Ultimately, ending the crisis in autistic people's mental health is not the job of one department. Young autistic people are facing mental health crisis because the education system is failing them, and they cannot access the support they need. Adults need employers that understand autism and the asset they can be in the workplace.



Health inequalities



Autistic people are more likely to experience both chronic physical health conditions⁵⁸ and mental health conditions. Despite this, getting access to the right healthcare support, from routine GP appointments to specialist advice and treatment for co-occurring chronic conditions, can be a fraught process.

For autistic people, time spent in healthcare settings is frequently characterised by a lack of sensory accommodations, communication difficulties and poor understanding of autism. Ultimately, the access to and quality of healthcare available for autistic people is often not sufficient to meet their needs and can be actively harmful.

Current situation

Autistic people experience some of the greatest health inequalities in society. Autism itself does not contribute to reduced life expectancy, but despite this, autistic people die around six years earlier than the general population, and autistic people who also have a learning disability die up to 15 years earlier.⁵⁹

Addressing the health inequalities and barriers to healthcare faced by autistic people is an important part of addressing discrimination in healthcare settings. This should be towards the top of the Government's agenda if they are to reduce health inequalities across the board and build an NHS fit for the 21st century.

Rosie's story

"My experiences of accessing healthcare as an autistic person are often met with raised eyebrows and expressions of disbelief, and yet my story is sadly one shared by many autistic individuals.

After hospitalisation for a seizure, I awoke confused in an unfamiliar place. The lights hurt my eyes, the bustles and beeps of the ward pricking at my brain. I was unable to speak or eat in such an overwhelming environment. Despite my friends being at my bedside, clearly explaining my autism and signing with me to communicate, a mental health assessment was still ordered. In the assessment, the doctor asked my friends to leave and demanded I spoke. I tried to write but my pen and paper were confiscated. I felt trapped, humiliated and terrified trying to force out words to explain that I was brought in for a seizure, not a mental health crisis.

The fear of possibly being sectioned caused me to panic and cry, and I was given a sedative, further justifying their narrative that I was in crisis. Upon discharge, I discovered several inappropriate referrals were made, including one to social services questioning my ability to live independently despite the fact I had been doing so successfully for some time.

I wish this was my only example but this pattern has repeated time and time again and for many more autistic people than just me. The fear of being misunderstood permeates every medical encounter, leaving me wracked by anxiety and often on the verge of tears. This fear distracts from legitimate medical concerns, as any worries I raise are credited to my obvious anxiety, delaying investigations and labelling me as a 'difficult' patient when I insist my experiences are more than my imagination.

I am left putting off medical care for as long as possible, partly from fear and partly from frustration that I will likely be misunderstood. There are endless appointments where I have been told I am too functional to be autistic, and just as many where they conclude I am too autistic to be functional.

It shouldn't have to be this hard, this often. Autistic people should be able to access healthcare without the realistic fear of their voices being lost or misinterpreted."



Daisy's story

"Statistically, autistic people are more likely to have additional health conditions. And yet, there is a distinct lack of education about autism and how to support autistic patients, which leads to inadequate healthcare, medical trauma and autistic people avoiding seeking help.

I struggle to communicate my thoughts, feelings and needs, so I need to bring a trusted person with me to all appointments to communicate on my behalf. I also struggle with sensory overstimulation from sounds, lights, smells and touch. My needs are not too difficult to accommodate, if medical professionals took the time to ask me what they are, and how they can best support me. But they never do. Instead, it is left up to me to advocate for myself.

I am unable to talk on the phone as I cannot listen, process what is being said and respond accurately, and in a timely manner. How am I supposed to navigate telephone appointments, rescheduling appointments or telephone assessments when I am unable to speak on the phone? The answer is I can't. When I do try to advocate for myself, people don't understand that these are my accessibility needs, not just preferences.

One of my consultants has repeatedly written that I have "autism well controlled" despite it being irrelevant to the appointment. I found this derogatory, as if I am a well-behaved dog rather than a human being. Another doctor has mistaken my autistic shutdown as being sedated which left me with medical trauma. I have been discharged from services for being 'difficult and uncooperative' when really I was just anxious and struggling to communicate.

A medical waiting room is not a nice environment for anyone, but for an autistic person, everything is heightened. The bright white overhead lighting burns my eyes. The cacophony of beeping machines are constant jabs into my skull. The chatter of people waiting and walking by is dizzying. The strong chemical smells make me nauseous. I'm exhausted before I have even had my appointment. But no sensory aids or alternatives are offered. Everyone else seems able to cope, so why do I feel like the world is ending? This is the reality of sensory overwhelm, just from waiting for an appointment. For me, every single healthcare interaction causes extreme anxiety, physical pain and discomfort, and leaves me with trauma."



Key statistics



80% of autistic adults report difficulty visiting a GP.⁶⁰



56% of autistic adults report not being understood at their GP appointment.⁶¹



Autistic people were over **seven times** more likely to report that sensory overwhelm makes it hard to focus on conversations with healthcare professionals.⁶²



Autistic people were over **three times** more likely to say they frequently leave a healthcare appointment feeling as though they did not receive any help at all.⁶³



For every ten non-autistic adults that report they can see a healthcare professional as often as they would like, **only four** autistic adults report the same.⁶⁴



Autistic adults are also between **20-36% less likely** than non-autistic adults to report being able to describe their symptoms, understand what their healthcare professional means or bring up a healthcare concern.⁶⁵

Rosie and Daisy's stories illustrate the complex and far-reaching negative consequences that healthcare barriers can result in for autistic people. A lack of accommodations and misunderstandings, as well as inappropriate and delayed treatment, is not just highly distressing and traumatic, but it can lead to issues being misdiagnosed or missed all together.

This is particularly the case for autistic people that are multiply marginalised. Black and global majority ethnic autistic people experience heightened inequality and disparity in accessing support and services, with evidence suggesting that in healthcare settings, support is less easily accessed, delayed, inappropriate for the individual or family, absent or limited.

By the time an autistic person receives the healthcare they need, they may have faced unnecessarily prolonged stays in hospitals and/or worsening symptoms and outcomes. This can result in a higher level of care eventually being required, unnecessary referrals and prolonged hospital stays.

These health inequalities can also prevent autistic people from seeking healthcare support when they need it. There is growing consensus behind the need to prioritise preventative healthcare to avoid escalating needs, but for many autistic people, timely access to care is not possible, with barriers including:

- trauma from previous negative experiences
- difficulties with recognising symptoms and establishing when they warrant healthcare
- communication barriers like needing to make appointments via phone-call
- a lack of accommodations for sensory sensitivity.

These factors which prevent autistic people from reaching out for healthcare support when they need it can result in untreated health concerns, requiring more extensive treatment and missing specialist referral and screening appointments.⁶⁶

What needs to change

Autistic people deserve equal treatment and proper understanding when accessing health services. For the Government to 'Build an NHS fit for the future - that is there when people need it, in a fairer Britain, where everyone lives well for longer',⁶⁷ healthcare must be made truly accessible for everyone, including autistic people.

In the first instance, the Government must make sure that autistic people are fully involved and included in the NHS 10-year plan. The healthcare barriers currently experienced by autistic people are not insurmountable and should be addressed urgently and effectively or autistic people will continue to experience unjustifiable and life-limiting health inequalities.

All healthcare staff should have completed the relevant tier of the Oliver McGowan Mandatory Training and receive ongoing opportunities to consolidate their knowledge to make sure that autistic people are met with understanding. It is not acceptable for staff that have not received this mandatory training to continue to provide services.⁶⁸

Every autistic person has different needs and preferences and for many, the most helpful thing a healthcare professional can do for them is to take the time to ask what can be done to accommodate them and allow them to feel more comfortable.

Simple adjustments can make a big difference. For example, allowing autistic people to wait for appointments in a quiet area, adjusting the lighting and providing prior explanation before using physical touch can all help to make

a healthcare setting more accessible to an autistic person.

The National Autistic Society Young Ambassadors, a group of young autistic campaigners, wrote to Wes Streeting in November 2024 calling for three steps to close the autism health gap:

Consult - directly with autistic people on our experiences of the healthcare system to learn about the healthcare barriers and poor health outcomes we face and the adjustments that could make a big difference.

Practice - put these adjustments into practice across all healthcare services to create an NHS fit for autistic people.

Review - continue to seek our views regularly, come back to us to find out what is working and what still needs to change.

The ask is not extensive and the solutions are achievable. With these measures in place, autistic people can hope to expect the same level of care and understanding as anybody else when simply trying to access the healthcare they need.



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Acknowledgements

We would like to thank everyone below for sharing their stories:

Sharren

Lauren

Tulsi

Moving Forward – Stephen and Ewan

Raivyn

Marsha

Rosie

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