

East Sussex
Autism Partnership Board

East Sussex All-Age Autism Action Plan

2025- 2027



Introduction

The East Sussex All-Age Autism Action Plan is for and about autistic people of any age, with a formal diagnosis of autism as well as those who identify as autistic.

It has been co-produced with people with lived experience, alongside representatives from East Sussex County Council, NHS and independent sector providers, including wellbeing, education and employment providers.

Most importantly it has been informed by the voices of autistic people, their families and carers. Throughout 2024 we consulted with the East Sussex autistic community and wider stakeholders to identify what is most important to autistic people living in East Sussex. As a result, this plan focuses on improving three areas:

- **Improving the health and wellbeing of autistic people**
- **Improving autistic children and young people's access to education and supporting positive transitions into adulthood**
- **Supporting autistic people into employment and helping them to sustain their employment**

The East Sussex All-Age Autism Action Plan is a three year plan. The East Sussex Autism Partnership Board has coordinated the development of the plan and will also be responsible for ensuring its implementation.

Aim

The aim of the East Sussex All-Age Autism Action Plan is to improve the lives of Autistic people, their families, carers, and wider support networks across East Sussex. We will do this through increasing autism awareness and improving education, employment, well-being and life opportunities for the Autistic community.



Background

East Sussex Autism Partnership Board

The [East Sussex Autism Partnership Board](#) was established as a response to the Autism Act (2009) to ensure that autistic people and their carers' voices are heard, and to improve the lives of local autistic people. The Board includes autistic members of the community, family and friend carers, local autism charity and independent sector representatives, NHS and County Council representatives.

National Autism Strategy

The latest [National Autism Strategy](#) was published in July 2021. This strategy follows the Autism Act (2009), and two previous adult autism strategies. The new strategy extends the scope to children and young people for the first time. East Sussex has therefore developed our Autism Partnership Board membership and the action plan to align with the priorities of the national strategy for all ages.

Partnership working

This Plan is a partnership approach and links to, and supports, a number of programmes of work in East Sussex, including:

- The [East Sussex Special Educational Needs and Disabilities \(SEND\) Strategy 2022-2025](#) sets out the priorities needed to support Children and Young People (CYP) with SEND, and their families, to enable them to achieve the best possible outcomes in life. These are:
 - Participation - my voice is heard and acted on

- Physical and mental health - my optimum health and wellbeing are supported
- Safety and security - I feel confident and secure
- Inclusion and belonging - I belong and feel valued for who I am
- Progress and achievement - I am supported to develop and achieve my goals.
- The [NHS Sussex Neurodevelopmental Pathway Programme](#) was established in 2022 to improve how the NHS supports people with neurodevelopmental needs, initially focussing on Autism and Attention-deficit hyperactivity disorder. The programme priorities are:
 - Introducing a needs-based approach to support people irrespective of diagnosis and associated reduced demand on this element of the pathway.
 - Clear and streamlined access to services and support, including digital support.
 - Streamlined approaches to assessment and post assessment across NHS services; and training more practitioners, primary care and mental health, to increase assessment capacity.



- The **Sussex Learning Disability and Autism Programme** aims to enable more people to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services. The three high level objectives of their strategy are:
 1. Close the gap in physical and mental health outcomes for people with a learning disability, autism, or both.
 2. Secure equitable access to early intervention and prevention services across the local NHS.
 3. Use the talent, knowledge, and skills of experts by experience to design better services.
- The **East Sussex Employability and Skills team** oversees a range of external multi-agency partnerships and employment and skills training programmes, which include:
 - supporting people into learning and work
 - working with schools and Further Education colleges to promote careers
 - bringing training providers and businesses together to address employment and skills needs of residents and employers.

Local funding context

This action plan will be implemented at a time when both the East Sussex County Council and NHS Sussex Integrated Care Board are facing significant funding challenges.

Nationally, health and social care is under pressure due to a combination of demographic, financial, and systemic factors. East Sussex is no stranger to this, facing unique challenges which impact on the need for support and services in the county. Around 25% of the East Sussex population is over 65 compared to a national figure of 18%, average wages remain lower than the national average and 30,000 people in the county are living in some of the most deprived areas of England. We have also seen a 40% increase in the average weekly cost of providing care in East Sussex since 2020. There is also evidence that the cost-of-living challenges have increased demand for care, as well as making people less able to afford their contribution towards the cost of care.

We have therefore worked with our stakeholders to identify priorities which are both achievable within current funding challenges, whilst also delivering meaningful change for the East Sussex autistic community.



How We Have Developed the Plan

To inform the development of the Plan, during 2024 we have:

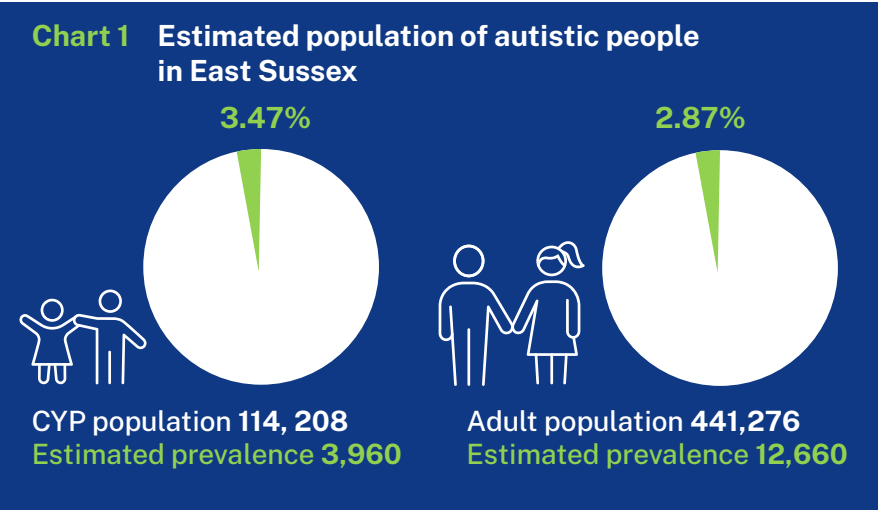
- Worked with Public Health to review local and national data to better understand the prevalence of autism in East Sussex.
- Carried out an online survey (April to June 2024) to gather the views of Autistic residents, parents and unpaid carers, and others with an interest on a range of topics. We received over 320 responses.
- Held 3 focus groups (July to September 2024) with Young Healthwatch, and autistic people accessing day opportunities to better understand what works wells and what could be improved to support them in their day-to-day life.
- Held 4 stakeholder workshops (September to October 2024), attended by over 80 people, to discuss the learning from the feedback, along with national and local research. Through these workshops we have developed 26 actions across 3 priority areas:
 - Improving the health and wellbeing of autistic people
 - Improving autistic children and young people's access to education and supporting positive transitions into adulthood
 - Supporting autistic people into employment and sustaining their employment



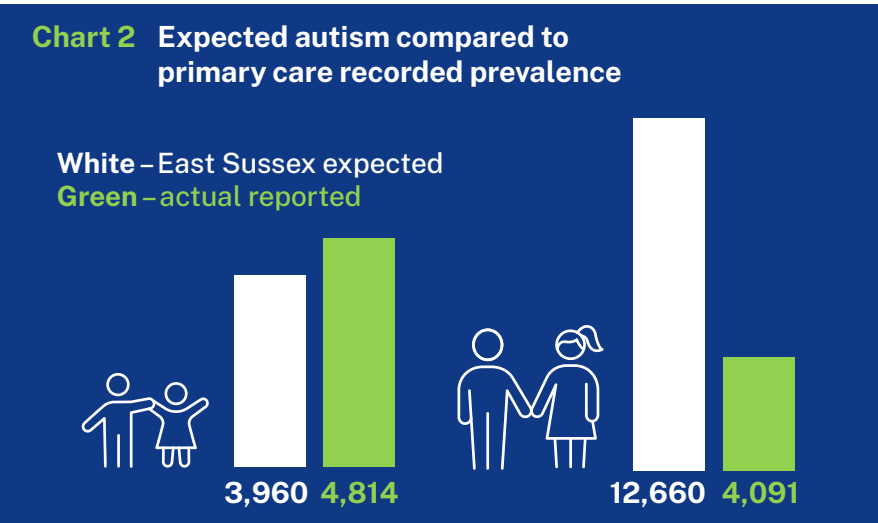
Local Context

The following information captures autism prevalence in East Sussex at a glance.

Population data

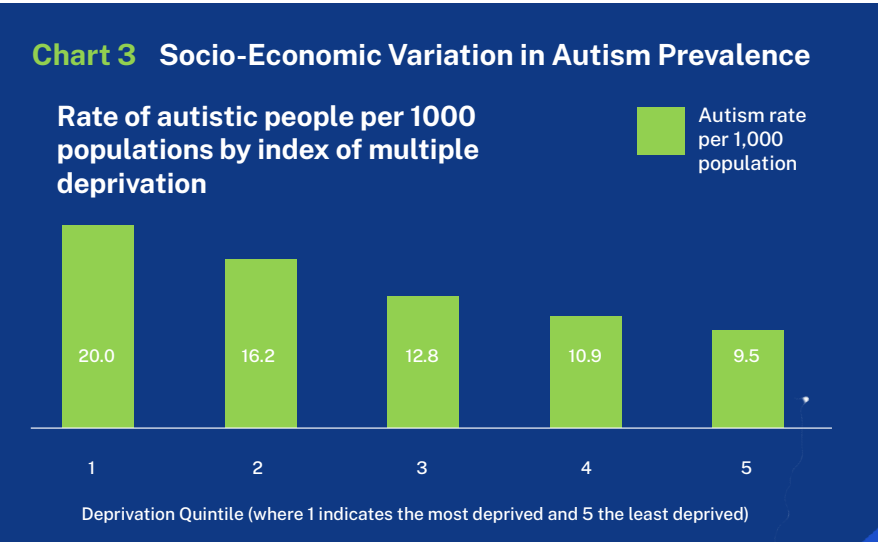


National estimates of prevalence show that approximately 3% of the East Sussex population is autistic (Chart 1). However, a review of primary care data shows that in comparison with the national estimates of prevalence, only 32% of autistic adults are currently recorded on the health system in East Sussex (Chart 2).

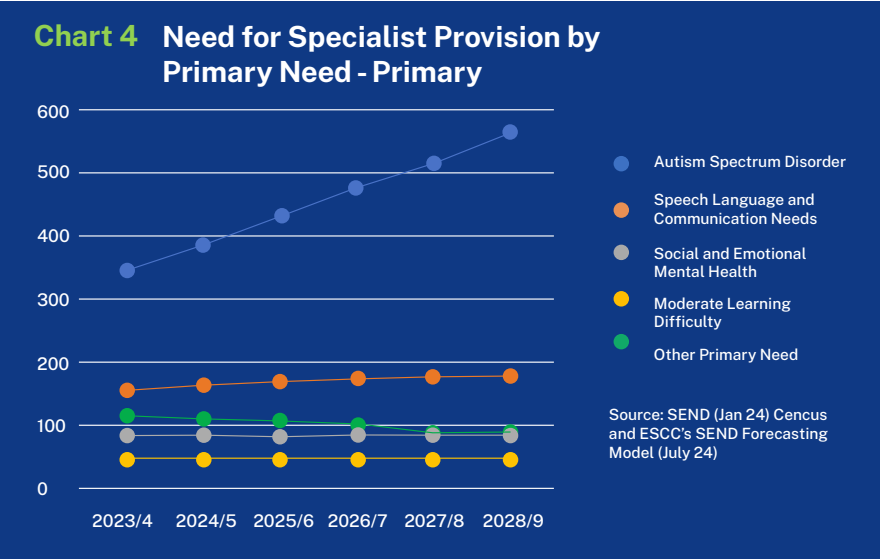


Of the autistic people known to primary care:

- 29% of autistic people are female, with 71% male.
- Black and minority ethnic groups including white minority groups (Irish, Gypsy or Irish Traveller, Roma, Other White) make up 11.7% of usual residents in East Sussex, compared to 10.9% of the autistic population.
- A higher proportion of autistic people live in the most deprived areas of East Sussex. We looked at where autistic people live in relation to the Index of Multiple Deprivation which is the current official measure of relative deprivation for small areas in England. It shows that 20 per 1000 population living in the most deprived areas on East Sussex are autistic, compared to 10 per 1000 population living in the least deprived areas (Chart 3)

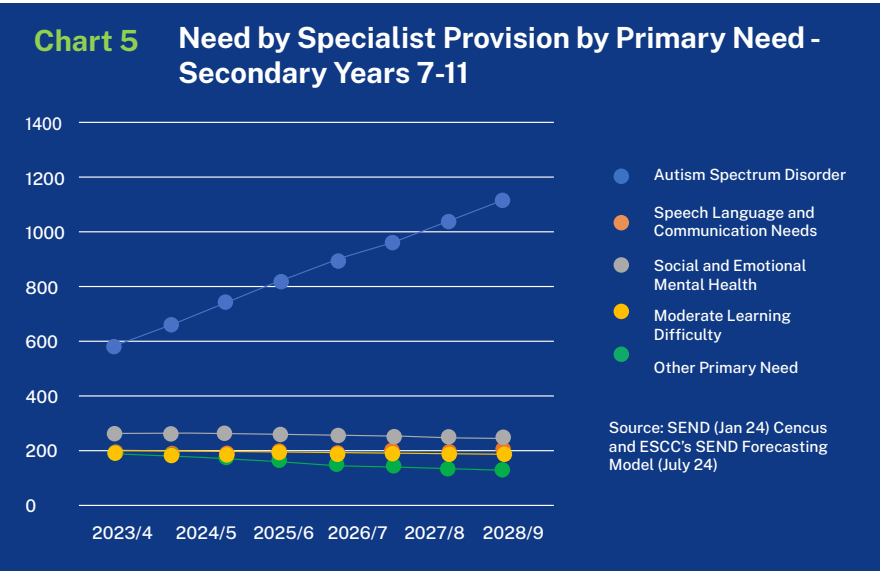


Education and care data



As of January 2025 there were 1,977 children with an Education Health and Care Plan (EHCP) and a primary need of autism in East Sussex.

In line with the national picture, autism is the most common primary need for those with EHCPs in East Sussex, and is the fastest growing need (Charts 4 and 5).



As of November 2024, there are currently 625 autistic people known to adult social care where autism is recorded.

15% of the known autistic population also have a learning disability.

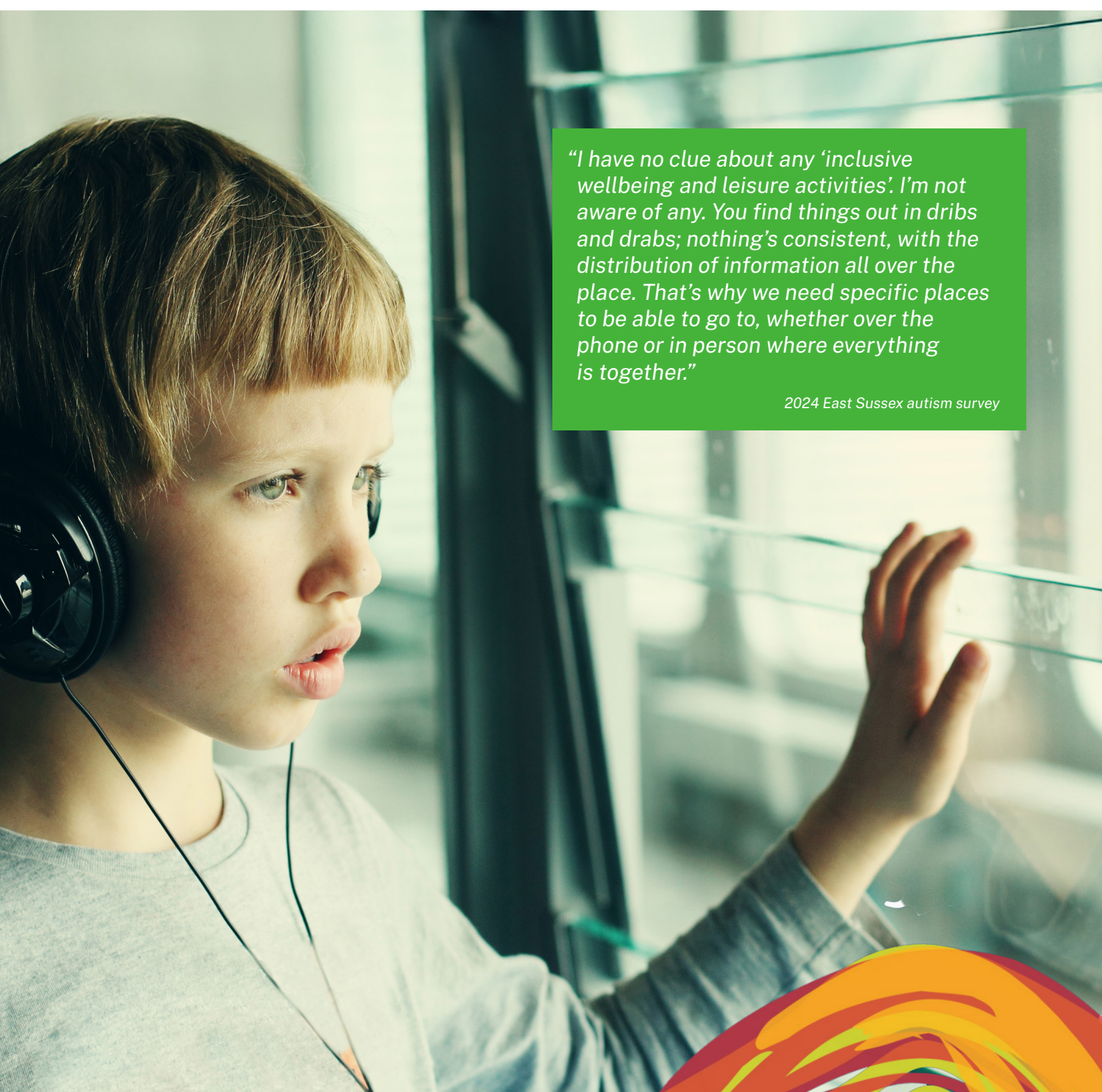
"It can be very hit or miss when it comes to dealing with various healthcare professionals for both myself and my children. I have had experience of GPs being extremely dismissive of our concerns, but others who have been very supportive. I think a lot more Neurodiversity training is required in all areas, but in particular females with autism/ADHD. I have been misdiagnosed my whole life, and a better understanding of women and masking would have helped health professionals greatly."

2024 East Sussex autism survey

Action Plan Priorities

Set out below are the 26 actions developed with our stakeholders across the three priority areas identified:

- Improving the health and wellbeing of autistic people
- Improving autistic children and young people's access to education and supporting positive transitions into adulthood
- Supporting autistic people into employment and helping them to sustain their employment



"I have no clue about any 'inclusive wellbeing and leisure activities'. I'm not aware of any. You find things out in dribs and drabs; nothing's consistent, with the distribution of information all over the place. That's why we need specific places to be able to go to, whether over the phone or in person where everything is together."

2024 East Sussex autism survey

Health and wellbeing: Improving the health and wellbeing of autistic people

What we have heard

Our survey for Autistic residents, parents and unpaid carers told us:

- The majority of respondents find it hard to access activities, support and services.
- There is poor understanding of Autism from others, including professionals and the public, and how it affects people's lives.
- East Sussex lacks inclusive, convenient and suitable options for social and community activity for Autistic people.
- Access to health and care services is hard for most respondents, with mental health being the hardest to access.
- The majority of people have to wait a long time for their diagnosis, sometimes years if they don't pay privately. Whilst waiting for a diagnosis many experience a decline in their circumstances.
- Lack of support following diagnosis was also raised as an issue.
- 55% of people said healthcare professional's understanding of autism was poor or very poor (12% good)
- 60% said it was hard to access social care support, with the main barriers being:
 - The were unable to get the support they needed
 - The criteria for support is too strict
 - Social care lacks understanding of autism
 - Social care lacks resources

What we will do now

1	Develop and promote accessible information and guidance on the neurodevelopmental diagnosis process and universal help available pre, during and post assessment, including crisis support	Year 1-3
2	Raise the profile of autism across East Sussex. Promote the work of autistic people and the benefits they bring to the community and workplaces. Recognise achievements and talents, and strengths	Year 1-3
3	Involve autistic people in the design of Integrated Community Teams to ensure services are accessible	Year 1-3
4	Promote examples of services that support autistic people well	Year 1-3
5	Pilot tailored support for autistic people rather than general signposting	Year 1-3
6	Increase education and improve the knowledge of autism of health and care professionals (particularly those within universal health and care settings)	Year 1
7	Embed autism awareness and understanding into all council departments	Year 1
8	Promote Autism health and care passports and alert cards	Year 1
9	Promote healthcare Digital Flags for reasonable adjustments to autistic people and healthcare professionals	Year 2-3
10	Develop Autism training champions across Health, Social Care and VCSE organisations	Year 2-3
11	Increase access to peer support groups for autistic people and their families	Year 3
12	Improve clinical environments, particularly diagnostic, to create more friendly and accessible spaces	Year 3
13	Implement autism annual health checks	Year 3



Education: Improving autistic children and young people’s access to education and supporting positive transitions into adulthood

What we have heard

One of the opening questions of our survey for Autistic residents, parents and unpaid carers asked ‘What are the top 3 most important things to change for autistic people’. Schools and colleges came out top, with 107 people feeding back it was most important to them.

Our survey for Autistic residents, parents and unpaid carers also told us that very few autistic people find it easy to access schools and colleges in East Sussex. 66% find it hard or very hard, and less than 3% said it was easy or very easy

We received an additional 500 comments about how education could be improved. The top five themes were:

- Lack of resources and appropriate settings
- The EHCP acquisition and appeals process
- School/college setting’s lack of understanding

- Insufficient training
- A need to avoid a ‘one size fits all approach’ to autism and reasonable adjustments

Conversely, we also asked what was working well in education. The most common answer was that support from schools and colleges, particularly primary schools was working well (23 comments). Frequently, feedback referred to an individual in a school which had made a significant difference.

The [East Sussex Parent Carer forum](#) also undertook a [survey](#) between October 2023 and January 2024, receiving 235 responses. Most of the families felt they were not receiving the SEND support/ provision that their children and young people needed or are entitled to. The most common message from parent carers was the continuing and exhausting battle they face with processes and services, and the need to fight the system for their child or young person’s needs to be met.

What we will do now

1	Develop profiling tool for schools to use to understand individual needs and how those needs can be met	Year 1
2	Ensure that appropriate education guidance, information and support is available to autistic children & Young People and their families	Year 1-2
3	Promote Autism training to all school staff, including improving understanding of masking, mental health and how a child’s environment impacts on their behaviour	Year 1-2
4	Promote curriculums / sharing of information that are inclusive and adaptive to ensure: ‘Every school/college sees itself as an education setting that meets the needs of autistic pupils’	Year 2-3
5	Increase understanding and support for autistic young people in secondary schools	Year 2-3
6	Improve the experience of transitions (primary to secondary / secondary to college) for autistic children and young people	Year 3

“Each individual has their own experiences. I know of several young people who cannot access secondary education due to the environment and demands. My son is doing well in a mainstream primary school; however, there are other children in his school who do not thrive in this environment. It’s really difficult to see. There does not appear to be appropriate support for kids who present with harder-to-manage behaviours.”

2024 East Sussex autism survey

Employment: Supporting autistic people into employment and helping them to sustain their employment

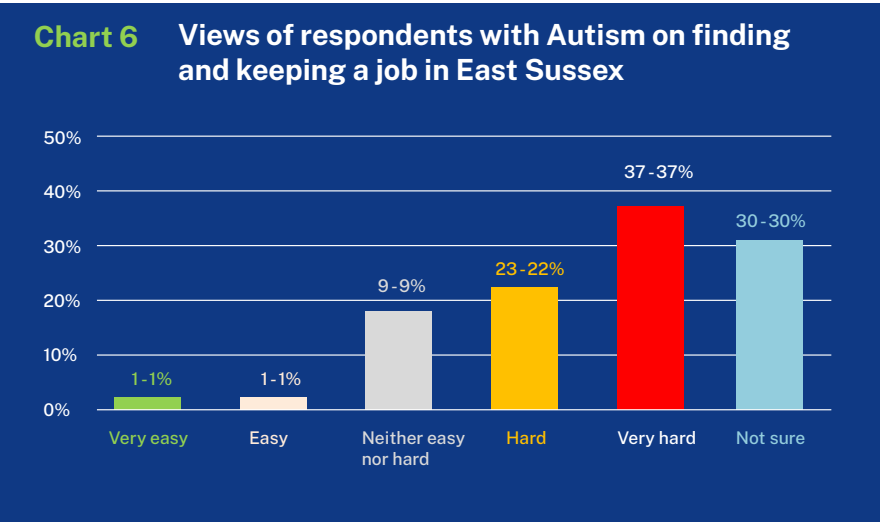
What we have heard

National research tells us:

- 21.7% of autistic adults are in employment (ONS, 2020).
- 6.25% of autistic adults hold full-time positions (National Autistic Society)
- Autistic people face the largest pay gap of all disability groups, receiving 1/3 less than non-disabled people on average (Buckland Review 2024)
- Autistic graduates are twice as likely to be unemployed after 15 months as non-disabled graduates, with only 36% finding full time work in this period. (Buckland Review 2024)
- 45% of neurodivergent individuals have been forced out or have quit their jobs due to misunderstandings related to their condition (National Autistic Society)
- Only 10% of organisations reported actively addressing neurodiversity in the workplace (2018 CIPD survey)

Our survey for Autistic residents, parents and unpaid carers told us:

- 59% of respondents said it is hard to find and keep a job (chart 6)
- The main barriers to employment are:
 - Employers’ lack of understanding
 - Employers lack of reasonable adjustments or accommodations
 - The person’s own outlook/ characteristics
 - The narrow range of employment options
 - Not having any support
 - Recruitment process is more favourable to neurotypical applicants
- Employment works well when there is:
 - Managerial support and employers’ understanding
 - Job coach support
 - Reasonable adjustments



“There is not much support for the whole process of finding, dealing with interviews, and then maintaining the job too. It is hard to find employers who are understanding and accommodating, especially surrounding communication, sensory overstimulation and burnout. Employers don’t understand when you can’t always maintain the same hours of work a week as some other weeks, or needing extra breaks or accommodations.”

2024 East Sussex autism survey

What we will do now

1	Publish and promote a centralised directory of employment support services in East Sussex	Year 1
2	Raise awareness and accessibility of resources to help employ more neurodivergent people	Year 1-2
3	Publish and promote guidance for making recruitment processes more accessible for neurodivergent people	Year 1-2
4	Further develop networks and peer support for employers working with and employing neurodivergent people	Year 1-2
5	Develop initial assessments for employment organisations to help to identify skills, suitable roles and reasonable adjustments	Year 2
6	Develop a programme of work to support young people and their families to consider their future employment choices, through helping them to identify their strengths, challenges and learning styles, and develop practical skills such as CV writing and interview techniques	Year 2
7	Develop support services that can act as a brokerage/advocate for employed autistic people who may need support to navigate work environment	Year 3

How will we measure success?

Each action will have an identified lead who will work with partners, including autistic people and their families, to oversee the implementation of the action. Progress will be reviewed by the East Sussex Autism Partnership Board, and an annual report will be presented to the East Sussex Health and Wellbeing Board.

It is important we also evaluate the impact the action plan has on improving the lives of Autistic people, their families, carers, and wider support networks. We will repeat the consultation at the end of the 3 years of action plan delivery, to further understand changes to the Autistic experience. This will include evaluating the following outcomes:

Health and Wellbeing

- I know how to find out about inclusive social activities in my local community
- I am able to access inclusive wellbeing and leisure activities
- I am able to connect with the autistic community in my preferred way
- I can access a timely assessment of my neurodevelopmental needs
- I feel empowered to ask for reasonable adjustments to support my needs
- I am able to access health care, delivered by the right people, at the right time
- I am able to access the care and support services I need
- If I have an unpaid carer or family member, they know how they can access support for themselves
- Health and care professionals have the knowledge and skills to support me as an Autistic person

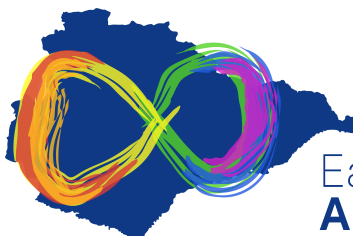
Education

- I can access an education setting that meets the needs of autistic pupils
- I feel empowered to ask for reasonable adjustments to support my needs
- I am supported to develop and achieve my goals
- School and college staff have the knowledge and skills to support me as an Autistic person

Employment

- I have access to clear information and advice about employment support available
- I feel empowered to ask for reasonable adjustments to support my needs
- I feel able to find and keep a job
- I know how to access support if I am looking to change jobs or develop my career





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