

Norfolk's All Age Autism Strategy

June 2024 to 2029



**NORFOLK
AUTISM
PARTNERSHIP**

Norfolk All Age Autism Partnership



A partnership of autistic people, parents, carers, voluntary and statutory organisations working together to achieve an autism-friendly Norfolk.



Norfolk County Council



Norfolk and Suffolk
NHS Foundation Trust

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Foreword and acknowledgements

This is Norfolk's refreshed strategy for improving the lives of autistic people living in Norfolk. It builds on and replaces the Norfolk All Age Autism Strategy for 2019 to 2024, 'My Autism, Our Lives, Our Norfolk'.

['My Autism, Our Lives, Our Norfolk'](#) called for a greater understanding of autism, so that autistic people can live fulfilling and rewarding lives. The Norfolk Autism Partnership Board (NAPB) works to improve services and support for autistic people of all ages. In 2019 the NAPB was facilitated by Norfolk County Council, but it is now supported by an independent organisation, giving it greater autonomy. We have seen some real improvements in Norfolk since 2019, such as autism awareness training available to everyone, which was co-produced by autistic people. And the [NAPB's website](#) is expanding all the time and is a valuable source of information for autistic people and their families.

The Covid pandemic had a major impact on many autistic people, making it harder for people to get support.¹ But we also learned some valuable lessons from the pandemic, such as the benefits of flexible working and new ways of providing support online.

Much more needs to be done to improve autistic people's lives in Norfolk. Autistic people and their families have told us that understanding of autism still needs to improve in society and across public services. They told us that improvements are particularly needed within mental health and other health services. Autism is not a mental illness, but it is estimated that 70 to 80% of autistic people experience mental ill health, and suicide is one of the leading causes of death.² Waiting times for an autism assessment have increased, with people waiting too long for an assessment. Autistic people and their families tell us that they are not getting the support they need due to the inequalities in services they experience. We also know that an inability to record and report accurate autism data both nationally and locally creates a real challenge to effective planning of appropriate services and support for those with a primary need of autism.

¹ [Left stranded: our new report into the impact of coronavirus \(autism.org.uk\)](#)

² [Autism and mental health.](#)

This strategy aims to build on the ambitions of 'My Autism, Our Lives, Our Norfolk'. It sets out what autistic people, their parents/carers and those supporting them have told us is important to them, and the changes that are needed to improve the lives of autistic people in Norfolk. It is co-produced by the NAPB, which includes people of all ages with lived experience of autism, including parents/carers. It also includes people from a wide variety of partner organisations such as individuals working in healthcare, social care, education, voluntary organisations, the police and Healthwatch. Everyone involved with the NAPB is committed to improving the life opportunities of all autistic people living in Norfolk.

This strategy uses the term 'autistic people'. This is because autistic members of the NAPB said that they prefer 'identity first' language ('autistic people' rather than 'people with autism'). Identity first language reflects the view of many autistic people that their autism is part of who they are, not something separate. However we recognise that there is no single way of describing autism that is universally accepted and preferred by everyone.³

Acknowledgement and special thanks to the following:

- The Autism Strategy Reference Group members for their hard work to develop this strategy and their creativity and innovative thinking.
- All members of the NAPB, past and present, who give their time, skills and experience. Their valuable contribution to improving services and support for autistic people of all ages is acknowledged.
- Those who completed the autism strategy questionnaire or attended a group or forum to refresh the strategy. All those who took part have had a major impact on this strategy by sharing their experiences and ideas.

³Which term should be used to describe autism?

Our vision

'My Autism, Our Lives, Our Norfolk' and this refreshed strategy set out a vision for the future:

Our Vision:

All autistic people, their parents/carers are accepted, understood and treated as equal members of the community. That there is a greater awareness and understanding of autism by people that live and work in Norfolk. That this understanding will enable autistic people to have the same opportunities as everyone else to live a fulfilling and rewarding life and achieve their life's ambitions.

This refreshed strategy sets out the areas which the Norfolk Autism Partnership will work on over the next five years, from 2024 to 2029 to achieve this vision. We will do this by working together to achieve the six priorities that autistic people have told us are important:



These six priorities are linked to the priorities of the [national strategy for autistic children, young people and adults: 2021 to 2026](#). The national strategy sets out the government's vision of the changes needed at a national level to improve autistic people's lives.

1 Improve understanding and inclusion of autism

By 2029, we want Norfolk to be a much more autism inclusive county, where Norfolk's autistic population are included in society, and feel safe and welcomed. We want to improve the understanding of autism within the general public, and among those providing support and services to autistic people.

2 Improve access to education and support transitions into adulthood

By 2029, we want autistic children and young people to get the right support so that every child and young person in Norfolk can flourish. We want transitions into adulthood to improve so that young people can live well in their communities, find work or continue in education.

3 Support adults into employment

By 2029, we want more autistic adults to be in employment. We want autistic people's experience of being in work to have improved, and for employers to be more confident about hiring and supporting autistic workers.

4 Tackle health inequalities for autistic people

By 2029, we want autistic people to be able to access the health support they need to live healthier lives. We want to see improved health outcomes and a reduction in the gap in life expectancy that currently exists for autistic people.

5 Build the right support in the community

By 2029, we want autistic people to be able to live well in their communities. We want improvements in support to mean that fewer autistic people reach crisis point. When autistic people spend time in hospital, we want them to be able to return home or move to suitable accommodation with the right support as soon as they are ready.

6 Improve support within the criminal and youth justice system

By 2029, we want autistic people who come into contact with the criminal and youth justice system to get the support that they need. Through early intervention, we want fewer autistic people to become victims of crime or to be convicted of a crime. We also want those who have been convicted of a crime to get the additional support they may need to fully engage with their sentence and rehabilitation.

Background

Why do we need a new autism strategy?

'[My Autism, Our Lives, Our Norfolk](#)' was a five year strategy from 2019 to 2024. The Norfolk Autism Partnership Board (NAPB) started work to refresh the strategy in June 2023. We want this refreshed strategy to build on 'My Autism, Our Lives, Our Norfolk'. It reflects the improvements that have happened since 2019, and the changes that autistic people in Norfolk have told us they want to see over the next five years, from 2024 to 2029. We also want to make sure that the refreshed strategy reflects changes in national guidance and policies, so that our local priorities and actions can be as effective as possible.

The Autism Act (2009) was the first national legislation and guidance specifically aimed at autistic people. In 2015, the government provided statutory guidance on implementing the Autism Act.⁴ This set out local authorities' and NHS organisations' duties to support autistic adults, and to have a local Autism Partnership Board in place. This led to the Norfolk Autism Partnership Board being set up in November 2017.

The statutory guidance also placed a duty on the government to produce and regularly review a national autism strategy to meet the needs of autistic adults in England. The most recent national strategy includes children and young people for the first time, as well as adults.⁵ This national strategy reflects many of the priority areas that were included in 'My Autism, Our Lives, Our Norfolk', such as employment, transitions, better community services and the justice system.

In refreshing this strategy, we also need to take account of other local strategies which may be relevant for autistic people. These strategies include the [learning disability](#), [SEND and alternative provision](#), [carers](#), suicide prevention and [eating disorders](#) strategies. Some of these local strategies are also in the process of being refreshed, so we have talked to people working on these other strategies. We talked to them to make sure that we are all working together to achieve the same priorities.

⁴[Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(publishing.service.gov.uk\)](#)

⁵[National strategy for autistic children young people and adults 2021 to 2026 - GOV.UK \(www.gov.uk\)](#)

Who is this strategy for?

This strategy is for autistic people of all ages, their parents, carers and families, those supporting them and anyone who has an interest in autism in Norfolk.

Autism is a lifelong developmental difference that affects how people communicate and how they experience the world around them.⁶ While autistic people share some similar characteristics, it is important to understand that everyone is unique, and autistic people have a variety of strengths as well as needs. Autism is not a learning disability or mental health condition, but autistic people can have co-occurring conditions such as a learning disability or health condition. Some autistic people are able to live independent lives, while others require specialist care and support.

The National Strategy reports that about one in 100 people are autistic, and that there are around 700,000 autistic adults and children in the UK.⁷ However, a recent study by researchers at University College London suggest that a more realistic estimate is that between 1 to 3% of people are autistic, and that there are over 1.2 million autistic people in the UK.⁸ This means, based on Norfolk's population there could be about 27,400 autistic people living in Norfolk.⁹ And based on the birthrate in 2021, there could be 237 autistic babies born each year in Norfolk.¹⁰

Approach to refresh the strategy

In June 2023, the Norfolk Autism Partnership Board (NAPB) set up an Autism Strategy Reference Group (the Strategy Group). This group included autistic people, members of the NAPB and statutory bodies working together to oversee the refresh of the strategy.

“
Being part of the Autism Strategy Reference Group enabled me to feel part of a caring community dedicated to making positive change for autistic people in Norfolk.
Autism Strategy Group Member
”

⁶<https://www.autism.org.uk/advice-and-guidance/what-is-autism>

⁷The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk)

⁸<https://www.ucl.ac.uk/news/2023/jun/number-autistic-people-england-may-be-twice-high-previous-thought>

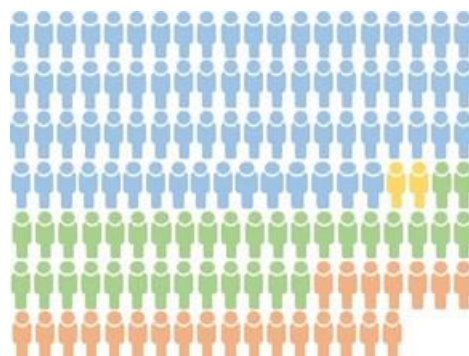
⁹<https://www.norfolkinsight.org.uk/wp-content/uploads/2023/08/Norfolk-Population-Overview-August-2023.pdf>

¹⁰[Norfolk Population Overview \(norfolkinsight.org.uk\)](http://www.norfolkinsight.org.uk)

The Strategy Group designed a 'You Said, We Did' document. This explained what has changed since 2019 in response to 'My Autism, Our Lives, Our Norfolk'. It also explained what partner organisations already plan to do to improve the lives of autistic people beyond 2024. An autistic member of the Strategy Group created [an animation](#) to provide this information in a different format, and an Easy Read version was also created. The Strategy Group designed and tested a questionnaire, to find out what is important to autistic people, their parents/carers and supporters. All of these communications were checked against the [Autism Friendly Top Tips guide](#) to make sure they were autism friendly.

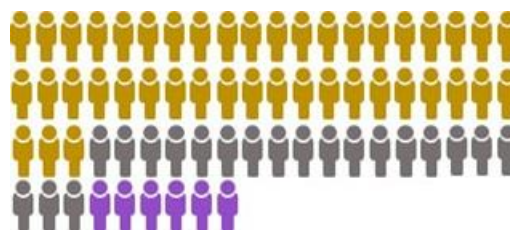
The Norfolk Autism Partnership (NAP) hosted a webpage to share the 'You Said, We Did' communications and the questionnaire, which could be completed online or as a workbook. They wrote to all members of the NAP to encourage people to take part, and shared details through partner organisations, voluntary groups and libraries across Norfolk. The questionnaire was completed by 137 people in total:

76 autistic adults (blue),
2 autistic young people (aged under 18) (yellow),
35 parents/carers or family members (green), and
24 professionals/other respondents (orange).



The Strategy Group arranged further activities in January and February 2024, to give people the opportunity to say more about what is important to them. A mix of online sessions and in-person sessions in Norfolk libraries were held. 69 people took part:

43 people through an online session (gold),
20 people through a library session (grey), and
6 people in a workshop for autistic prisoners at
Norwich Prison (purple).



The views we gathered through the questionnaire and the sessions led to the six priorities listed on page 6. 574 individual comments were noted from the questionnaire and sessions and were grouped into key themes. These key themes are reflected throughout this strategy in the sections headed 'What is important to people?'

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1

Improve understanding and inclusion of autism

By 2029, we want Norfolk to be a much more autism inclusive county, where Norfolk's autistic population are included in society, and feel safe and welcomed. We want to improve the understanding of autism within the general public, and among those providing support and services to autistic people.

What we know nationally

The national strategy reports that awareness of autism has increased, since the introduction of the Autism Act in 2009. It is estimated that 99.5% of the public are now aware of autism.¹¹ Although there is more awareness, there is still a significant lack of understanding about autism among the public, including what it means to be autistic and the diversity of autism. Just 24% of autistic adults and 26% of family members think public understanding has improved since the introduction of the Autism Act.¹²

The Equality Act 2010 places a legal requirement on public services to eliminate discrimination and advance equality of opportunities for disabled people. It also requires service providers, employers and businesses to provide reasonable adjustments for disabled people. This includes autistic people, with or without a diagnosis, provided that their autism has a substantial effect on their ability to carry out day to day activities.¹³

Many public sector services and other organisations are taking steps to become more autism inclusive. However, autistic people still face stigma and prejudice when accessing services or just going about their daily lives.¹⁴ Many autistic people feel excluded from public spaces because these can be overwhelming, busy or noisy and because staff or the public may react negatively to autistic people. The national strategy also identifies that transport is a key issue and is central to autistic people and their families being included in their community and being able to find employment. Many autistic people find public transport inaccessible because of how anxiety-inducing, noisy and busy it can be.

¹¹[The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/614247/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf)

¹²[APPGA-Autism-Act-Inquiry-Report.pdf \(pearsfoundation.org.uk\)](https://www.pearsfoundation.org.uk/wp-content/uploads/2019/07/APPGA-Autism-Act-Inquiry-Report.pdf)

¹³[Check if you're protected from disability discrimination - Citizens Advice](https://www.citizensadvice.org.uk/disability-and-health/autism/autism-act-2009/check-if-youre-protected-from-disability-discrimination/)

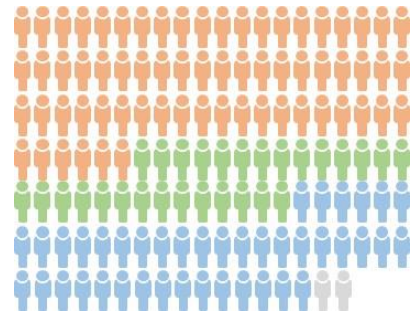
¹⁴[The Autistica Attitudes Index | Autistica](https://www.autistica.org.uk/what-we-do/attitudes-index/)

What we know in Norfolk

'My Autism, Our Lives, Our Norfolk' included autism awareness as a priority for 2019 to 2024. Our new priority for this strategy reflects the need to move on from awareness to better understanding and inclusion.

Our questionnaire asked people whether they thought that autistic people are more included within their communities now, compared with 2019.

48% said they were unsure (orange),
21% said they are more included (green),
30% said they are not more included (blue),
1% did not answer the question (grey).



[Autism awareness e-learning](#) is available free of charge to anyone via the Norfolk Autism Partnership website. There is also a more detailed one day 'Understanding Autism' course. The Norfolk Autism Partnership co-produced, designed and created both courses with the help of Norfolk County Council and Norfolk and Suffolk NHS Foundation Trust. The courses have been quality checked and endorsed by the University of East Anglia and are annually updated.

People told us that although there is more awareness of autism, there is still a lot to be done to improve the understanding of autism within society, and in public services. In particular, autistic people raised concerns about the lack of autism awareness among staff in primary care, including GP surgeries, and the need for mandatory training to address this. They also talked about the need for better understanding among employers, as well as in schools and a wide range of other settings.

People said that there is a need for clear information about support for autistic people in Norfolk. They also told us about the importance of autistic people working with services to create information and training, and of advocacy to support people when needed. And they told us that safe spaces are needed in the community and in hospitals.

What is important to people

I note there is in general, a shift (for the better) in people's awareness and understanding of the needs of autistic people and there are more considerations in services (i.e. supermarkets, cinemas, etc) of how to adjust to meet the needs of autistic people. Norfolk Resident

Awareness seems to have increased, but I don't feel like it has translated to real inclusion. Norfolk Resident

Better understanding of autism in society

- Many people said that autism training for employers or for those providing services in community such as opticians, solicitors and hairdressers is needed. Training could also help family members of autistic people.
- People said there needs to be more understanding of autism among the general public. This includes understanding of meltdowns and shutdowns, so that people respond in a way that is helpful.
- People said that autism should be recognised as a different way of thinking to break down stereotypes.
- People said that autism should be celebrated in society. This includes having positive role models and using celebrities.
- People said that leisure services and social groups which are open to everyone (such as Scouts and Brownies) need to make adjustments so that autistic people can take part more easily.
- People said that autism friendly transport needs to be widely available, so that autistic people can get out and about, particularly if they live in rural areas.
- People said that autism alert cards should be promoted, so that autistic people can choose to use them, and the general public have a better understanding of what they can do to support autistic people.

- People said there could be a kitemark scheme to recognise organisations which are supporting autistic people well.

Understanding of autism in public services

- Many people said that more training is needed for staff in settings such as schools, the police, job centres and prisons, to improve the understanding of autism. This includes making sure that staff put training into practice, and that training is mandatory. This will make sure that all staff who work with autistic people have the right skills and knowledge.
- Many people said that it is important to make reasonable adjustments based on the needs of the autistic person, regardless of whether they have a diagnosis. For example, providing a quiet place in hospitals and allowing more time to explain things. People said that reasonable adjustments should be made in schools based on the child's needs, rather than requiring a diagnosis.
- Many people said that there should be more training for staff in health and social care services. They said it is important that clinical and administrative staff in hospitals, GP surgeries, dentists and mental health services undertake the right level of training for their role.
- People said that it is important that professionals understand sensory differences (such as different ways of perceiving pain), and that they understand demand avoidance and the impact of previous trauma.
- People said there are examples of good practice in healthcare settings and schools. This good practice should be shared widely so that other services can learn from them.

Information and Resources

- Many people said that a Norfolk directory of autism support should be created, so that autistic people and their families know what is available, and how to access it.

Co-production

- People said that co-production is important. They said that information for autistic people should be co-produced, and that autistic people should be fully involved in creating the plan to deliver this strategy and monitoring it. They also said that autistic people should be involved in creating training courses (such as the [free autism awareness e-learning](#)) and that it is important for autism training to be co-presented by autistic people.
- People said that the Norfolk Autism Partnership Board should reach out to younger people, to make sure that they are represented on the Board.

Advocacy

- People said that independent advocacy should be available whenever autistic people need it. This could be to support them when accessing services such as health and social care or when applying for benefits.

Safe spaces

- People said there is a need for safe places in the community and in hospitals. These could also provide a quiet place for autistic people when they need it.

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2

Improve access to education and support transitions into adulthood

By 2029, we want autistic children and young people to get the right support so that every child and young person in Norfolk can flourish. We want transitions into adulthood to improve so that young people can live well in their communities, find work or continue in education.

What we know nationally

The national strategy tells us that a growing number of children and young people are being diagnosed as autistic, with special educational needs data suggesting that 1.8% of all pupils in England now have an autism diagnosis.¹⁵ In spite of this, many autistic children and young people are still having poor experiences at school and are struggling in the transition to adult life. The national strategy highlights evidence that autistic children and young people often struggle to get support they need through the Special Educational Needs and Disabilities (SEND) system, including being able to access support early enough from health and social care, as well as education. In addition, staff often lack the skills needed to put in place the right plans and support for autistic young people.¹⁶

What we know in Norfolk

The Norfolk Joint Strategic Needs Assessment for children and young people with SEND published in May 2022 found that 49% of children and young people (1267 children) on the Norfolk Register of Disabled Children in 2019 were autistic.¹⁷ The JSNA also identified that the most common primary need for children in special schools is Autistic Spectrum Disorder, although the proportion is lower than the national figure (28.7% of special school pupils in Norfolk, compared to 32.4% in England).

Norfolk now has two specialist autism schools: The Wherry School in Norwich which opened in 2017, and the Duke of Lancaster school in Fakenham which opened in January 2022. Two new specialist schools are planned for 2026: a school for children with communication and interaction needs in Downham Market, and a school for children with complex needs in Great Yarmouth. Norfolk also has 13 autism specialist resource bases (SRBs) attached to mainstream schools, but the JSNA found that there are not enough places available for autistic children and young people.

¹⁵Special educational needs in England, Academic year 2022/23 – Explore education statistics – GOV.UK (explore-education-statistics.service.gov.uk)

¹⁶The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK (www.gov.uk)

¹⁷Norfolk Joint Strategic Needs Assessment for children and young people with SEND

Norfolk County Council set up a [Preparing for Adult Life team](#) in 2020 to support young people who are likely to need support from Adult Social Services. The proportion of young people turning 18 and supported by the team whose primary need is autism has increased each year, rising from 13% in 2021 to 2022 to 26% in 2023 to 2024.¹⁸

People told us that the support for autistic children and young people in education settings needs to be improved, along with better communication with families. They also said that better support is needed for those who are not in school as some parents are not home educating through choice, but because a school cannot meet their child's needs. And people said that improvements need to be made for the transition into adulthood.

Our plans to achieve this priority need to reflect the [SEND and Alternative Provision Strategy](#). We will identify where actions planned as a result of that strategy will help us to achieve the priorities within this refreshed strategy.

What is important to people

Better planning for this transition period, thinking about aspirations, developing independence skills and access to mental health support/support with creating and maintaining healthy relationships.
Norfolk Resident

My son has no idea how to move forward after college and is very stressed about what the future may bring. Norfolk Resident

Support in schools, colleges and other education settings

- People said that good quality support in mainstream schools, colleges and universities is important. This includes support continuing from one setting to another (for example, primary to secondary school). It also includes understanding of autistic young people's mental health and sensory needs, and support for those with lower level needs, not just those with complex needs.
- People said that better resources are needed to enable teachers to support autistic students. These should also be shared with parents for a consistent approach.

¹⁸Data provided by Norfolk County Council.

- People said that schools and colleges could learn from each other by sharing good practice.
- People said that it can be very difficult to access an Education Health and Care Plan (EHCP) for those who need it, and the wait to get an EHCP should be reduced. People said that schools and colleges should be held to account if they do not provide the support listed in an EHCP.
- People said that more specialist schools for autistic students are needed, as well as better access to remote learning for those who are struggling to attend school. People said that more flexibility could enable young people to access college courses when they are ready for them, rather than being limited by their age.
- People said that autistic children and young people should get support in schools to enable them to make and keep friends. People also said that bullying within schools needs to be better addressed.

Communication

- People said that the voices of parents and children needs to be heard in education settings, as parents can feel that they are not listened to.
- People said that autistic young people need more support to learn to speak for themselves as they become adults. They said families need better information about how they can support their child to make their own decisions, and what happens if the young person is not able to make a decision for themselves.

Support for home educating families, and young people who are not in school

- People said it would be helpful if resources used by schools could be shared with families, so that they can use them as well.

Transitions into adulthood

- People said autistic young people need support to make the transition from school to college, and from education to work. This includes schools and colleges knowing about options for young people to move on to.
- People said that careers advice should focus on the autistic young person's strengths and their hopes for the future.
- People said that planning for the transition into adulthood should start in Year 9 for all autistic young people, not just those with an EHCP.
- People said that continuity is important in transitions within health care, social care and education, so that autistic young people do not suddenly lose support, or find they are being supported in a very different way.
- People said that waiting times for support from the Preparing for Adult Life Team need to be reduced, so that they can get involved earlier.

3

Support adults into employment

By 2029, we want more autistic adults to be in employment. We want autistic people's experience of being in work to have improved, and for employers to be more confident about hiring and supporting autistic workers.

What we know nationally

The national strategy tells us that there is a significant employment gap for autistic people. The Buckland Review of Autism Employment (published in February 2024) identified that only around 3 in 10 working age autistic people are in employment.¹⁹ This compares with around 5 in 10 for all disabled people and 8 in 10 for non-disabled people. Autistic people also face the largest pay gap of all disability groups, receiving a third less than non-disabled people on average. Autistic graduates are twice as likely to be unemployed after 15 months than non-disabled graduates and are more likely to be overqualified for the job they have.

Barriers to work for autistic people identified by the Buckland Review include poor preparation by employers, unfair hiring practices, unclear processes and outdated attitudes. Once in a job, many autistic people do not receive the support or adjustments they need. Only around 35% of autistic employees are fully open about being autistic at work, and the most common time for employees to disclose their autism is after starting a job. This highlights a persistent and well-founded fear of discrimination during the recruitment process.

What we know in Norfolk

Using the estimated figures for the number of autistic people in Norfolk referred to [above](#), there could be about 14,200 autistic people aged 18 to 64 in Norfolk.²⁰ If only 3 in 10 autistic people of working age are employed, then there could be almost 10,000 autistic people of working age who are not in employment in Norfolk.

New employment schemes to support people with long-term conditions, including autistic people, have been established since 2019. These include the [Local Supported Employment](#) programme (available from late 2022 until March 2025) and [Working Well Norfolk](#). There is also the [Norfolk Employment Service](#) for people supported by Adult Social Services. In addition, the [Universal Support Scheme](#), funded by the Department of Work and Pensions, is currently being rolled out across the country. This is likely to come to Norfolk in late 2024 or early 2025.

¹⁹[Buckland Review of Autism Employment](#)

²⁰Data shared by Norfolk County Council

People have told us that more needs to be done to support autistic people to get and keep a job and to support employers of autistic people. They also told us that there need to be more routes into employment and education for autistic adults.

What is important to people

“ Many autistic people find themselves stuck in volunteering or unhealthy work environments. I think a priority needs to be to support us to find paid, sustainable employment...
Norfolk Resident ”

“ ... support for adults when they are already in employment...
Norfolk Resident ”

Getting a job

- People said that autistic people need support to access employment based on their strengths and interests.
- People said that there are many alternatives to traditional employment which could be considered. These include apprenticeships, supported internships, self-employment, part-time or flexible working, and paid peer support roles. Being able to work or study from home also creates more opportunities for some autistic people.
- People said that recruitment processes should be adapted so that they are based on autistic people's strengths and an understanding of the challenges they experience. For example, doing a job trial rather than a traditional interview.

Keeping a job

- People said that employers could provide a mentor for autistic employees when appropriate. Having one person to go to would make it easier for many autistic people to maintain their job.
- People said that more support should be given to autistic employees to help them to manage stress and issues at work. Autistic people sometimes feel that Human Resources processes around absence do not recognise their needs.

- People said that autism friendly information on employment rights would be helpful. This would help autistic employees to know what support they can expect their employer to provide, and what their employer is legally required to do.
- People said that bullying in the workplace should be addressed.
- People said that autistic people should be made aware of the support available through the [Access to Work](#) scheme.

Support for employers

- People said that there should be more information and support available to employers to help them recruit and support autistic employees.
- People said employers could share good practice with each other and be encouraged to sign up to the [Disability Confident](#) scheme. The needs of autistic people could be specifically considered, for example as a separate kitemark.

Routes into employment and education for adults

- People said that there should be more supported employment settings for autistic people who need a higher level of support.
- People said that volunteering and work experience could provide more routes into work for autistic people.
- People said there should be more targeted support for autistic people who are on benefits, to support them to get into work.
- People said that support should be available to enable autistic adults to access education throughout their life.

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4

Tackle health inequalities for autistic people

By 2029, we want autistic people to be able to access the health support they need to live healthier lives. We want to see improved health outcomes and a reduction in the gap in life expectancy that currently exists for autistic people.

What we know nationally

The national strategy highlights that many people are waiting a long time for an autism diagnostic assessment. NHS data shows that in December 2023 over 170,000 people were waiting for an autism assessment in England, a 47% increase from the previous year.²¹

The national strategy also tells us that autistic people have poorer physical health outcomes and a lower life expectancy than the general population.²² Many possible reasons for this gap have been suggested, including poor understanding of autism among health and care staff, which can lead to signs of illness being overlooked. Without the right understanding, autistic people can miss out on adjustments needed for them to engage in medical appointments, which can lead to distressing experiences and avoiding seeking medical attention.

It is estimated that 70 to 80% of autistic people experience mental ill health. This could include anxiety, depression, eating disorders or psychosis.²³ It is recognised that there are not enough of the right type of community services, and not enough mental health professionals who properly understand autism.²⁴

Autism annual health checks are currently being piloted in other parts of England, to tackle the causes of poor health in autistic people and improve their physical and mental health.²⁵ These health checks already exist for people with learning disabilities, and there is evidence that they can improve health outcomes.²⁶ They are not yet available for autistic people who do not have a learning disability in Norfolk. Autistica is working with NHS England to carry out research into the effectiveness of these checks for autistic people and has created a [Health Checks Plan](#) to ensure every autistic person is offered an annual health check by 2030.

²¹News item [Autism assessment waiting times](#)

²²[Premature death of autistic people in the UK investigated for the first time | UCL News - UCL – University College London](#)

²³[Challenges autistic people face | Autistica](#)

²⁴[Mental Health \(autism.org.uk\)](#)

²⁵[Autistica releases plan to ensure every autistic adult is offered a yearly, tailored health check by 2030 | Autistica](#)

²⁶[Better Health and Care for All \(nhr.ac.uk\)](#)

The [learning from lives and deaths – people with a learning disability and autistic people \(LeDeR\)](#) programme was expanded in January 2022 to include autistic adults who do not have a learning disability. The number of LeDeR reviews for autistic people without a learning disability completed in 2022 was small, and awareness of the programme needs to be increased. The annual report found that suicide was the leading cause of death for autistic adults referred for a review.²⁷ [The national suicide prevention in England: 5-year cross-sector strategy](#) identifies autistic people as a priority group, reflecting the evidence that autistic people are up to seven times more likely to die by suicide than others, with a need for action to address this.²⁸

What we know in Norfolk

People have told us that more needs to be done to tackle health inequalities in Norfolk.

The NHS publishes statistics relating to waiting times for autism assessments on the [NHS Digital website](#). However, not all diagnostic services report in this way, meaning that this data is not always accurate for Norfolk. While improvements to the accuracy of the NHS Digital data are being made, commissioners report statistics to the NAPB. In January 2024, it was reported that there were 9290 children (aged under 18) waiting for a neurodevelopmental assessment in Norfolk and Waveney. And there were 954 adults in Norfolk waiting for an autism diagnostic assessment.

Norfolk's situation mirrors that across England, with waiting lists at unsustainable levels. Diagnostic services for both adults and children are unable to meet the NICE guidance stating that no one should wait longer than 13 weeks for their first appointment,²⁹ or the NHS 18 week 'Referral to Treatment' target.³⁰ Actions to reduce the waiting time for an adult autism assessment were taken in 2022 to 2023, using one off funding to complete 1119 assessments. Similar funding has been allocated for children's neurodevelopmental assessments, and this work is underway. This one off funding has helped temporarily, but increasing numbers of people being referred for assessment means that waiting times are increasing. If referrals continue at their present rate and action is not taken, the waiting times will continue to increase each month.

²⁷[Learning from Lives and Deaths - people with a learning disability and autistic people \(LeDeR\) - King's College London \(kcl.ac.uk\)](#)

²⁸[Suicide and autism | Autistica](#)

²⁹[Autism assessment waiting times](#)

³⁰[NHS England » Referral to treatment](#)

In most cases, people have a right to choose an alternative service to complete their autism assessment, provided that service is approved by the NHS.³¹ However, many people (including professionals) are not aware of this option.

People told us that more needs to be done to improve the support available before and after a diagnosis, and throughout life. There is some support available, such as advice and guidance from [Family Action](#) for parents and carers of children waiting for a neurodevelopmental assessment, or who have recently been diagnosed with autism or ADHD. Some sessions of post diagnostic support are also now available for adults who have been diagnosed, and a resource pack is [available online](#). There is a Living Well with Autism course which was co-produced with people with lived experience of autism, available through the [Recovery College](#) run by Norfolk and Suffolk Foundation Trust.

However, people told us that there is not enough support while waiting for a diagnosis and limited support available post diagnosis. They told us that support needs to be improved before and after diagnosis, and that ongoing support, including therapy adapted to meet their needs, should be available. People also told us that there is a lack of clinical support for issues such as sensory needs and communication.

More also needs to be done to improve mental health support across Norfolk to prevent autistic people from reaching a crisis, and for those in a crisis. People talked about the need to improve mental health services, to ensure that they are appropriate for autistic people and that mental health support is not refused due to them being autistic. People told us they are not able to access mental health support when they need it. They also talked about the difficulties resulting from a misdiagnosis (when autism is not recognised), but also how autism may overlap or be overshadowed by other conditions. This can make it hard for autistic people to have their needs met, and for professionals to offer the right support.

The local suicide prevention strategy is currently being refreshed, and recognises that autistic people are a priority group. Our plans to achieve this priority need to reflect the local suicide prevention strategy. We will work with Public Health and other organisations to consider how the actions in our strategy plan can link to the local suicide prevention strategy and improve support for autistic people.

³¹[Patient choice at the point of referral - Norfolk & Waveney Integrated Care System \(ICS\) \(improvinglivesnw.org.uk\)](#)

Our plans also need to take into account the local [Eating Disorders Strategy](#), as research suggests that autistic people may be more likely to experience eating disorders.³² We will identify where actions planned as a result of that strategy will help us to achieve the priorities within this strategy.

What is important to people

“ ASD affects the whole experience of healthcare, and the long wait times and difficulty getting diagnosed is a significant barrier to accessing the correct healthcare and resources.
Norfolk Resident

“ People are waiting too long for a diagnosis that can put people off a diagnosis when it is needed.
Norfolk Resident

Diagnosis

- Many people said that waiting times for an autism diagnosis should be reduced.
- People said that the tools used for diagnostic assessment should be appropriate for all groups, such as women and girls, and that it is important that staff keep up to date as the understanding of autism changes.
- People said that pre and post diagnostic information and support are important. This includes information and support around regulating emotions, understanding masking and sensory differences.
- People said that there needs to be more awareness that when autism has not been recognised, this can lead to misdiagnosis of other conditions. Misdiagnosis can lead to inappropriate medication.
- People said that the diagnostic pathways need to be improved for adults who may need assessments for more than one condition, such as autism and ADHD.
- People said that a private diagnosis was not accepted by their GP in some cases, and it should be.

³²[Eating disorders \(autism.org.uk\)](https://www.autism.org.uk)

Health services

- People said that autism annual health checks would be very helpful. These have been piloted in some parts of the country but are not yet available in Norfolk.
- People said that [My health passports](#) need to be more widely promoted and followed by health professionals.
- People said that there needs to be better access to specialist health services such as Speech and Language Therapy, sensory integration assessments and support for ARFID (Avoidant Restrictive Food Intake Disorder).
- People said the support offered by the Learning Disability and Autism Nurses in the acute hospitals needs to be better known about, and that it would be helpful if it was available out of hours.

Mental health services

- People said that mental health support for autistic people needs to be more available. This includes therapy and counselling being adapted so that they are appropriate for autistic people.
- People said that better support is needed to stop autistic people going into crisis. People also said that more support should be available when autistic people are in crisis.
- People said that crisis telephone support should be available for autistic people and that there should be an option to speak to someone with expertise in autism.

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Build the right support in the community

By 2029, we want autistic people to be able to live well in their communities. We want improvements in support to mean that fewer autistic people reach crisis point. When autistic people spend time in hospital, we want them to be able to return home or move to suitable accommodation with the right support as soon as they are ready.

What we know nationally

The [Building the Right Support](#) national plan was updated in 2022, and states that all autistic people should be able to live full lives in their community, in their home, with access to the care that is right for them, when and where they need it.³³ Too many autistic people (particularly teenagers and young adults) are still being admitted into inpatient hospital settings, often because they struggle to access community support (including social care, mental health and housing support) before their needs escalate.³⁴

In February 2024, NHS data shows that there were 2,045 autistic people and people with learning disabilities in mental health hospitals in England.³⁵ 67% of these people are autistic. There are 210 under 18 year olds in inpatient units who are autistic or have a learning disability, and 93% of them are autistic. There has been some progress in moving people with learning disabilities out of hospitals and into the community. However, the number of autistic people who do not have a learning disability detained in mental health hospitals has increased by 100% since 2015.³⁶

What we know in Norfolk

NHS data indicates that there were 35 people with learning disabilities and autistic people in inpatient settings in Norfolk and Waveney in February 2024.³⁷ As a proportion of the population, this is slightly below the average for England. This number included 15 autistic people, 5 autistic people who also had a learning disability and 15 people with learning disabilities.

³³[Building the Right Support Action Plan - GOV.UK \(www.gov.uk\)](#)

³⁴[The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV.UK \(www.gov.uk\)](#)

³⁵[Assuring Transformation NHS data](#)

³⁶[Number of autistic people in mental health hospitals: latest data \(autism.org.uk\)](#)

³⁷[NHS Assuring Transformation data: Learning disability services monthly statistics from Assuring Transformation dataset: Data tables - NHS England Digital](#)

The Norfolk and Waveney Integrated Care System requested a [Building the Right Support peer review](#) in 2022 to look at how services for autistic people and people with learning disabilities could be improved. This involved professionals and people with lived experience from other areas visiting Norfolk and Waveney and giving feedback about the support and services available. The peer review highlighted the need to address the inequalities in services that are experienced by autistic people. [Building The Right Support](#) covers both autistic people and people with learning disability both nationally and locally. Looking separately at the needs of autistic people could provide a clearer focus, to help address the recognised inequalities in services.

Some new services for autistic people have been established in Norfolk since 2019. These include a new short-term adult social care service for adults with emerging social care needs, which was set up in January 2024. [Titan travel training](#) has been extended to autistic adults known to Adult Social Services, and some assistive technology gadgets and apps can be provided for autistic adults living in their own homes.³⁸ And an award-winning care phone was rolled out by Adult Social Services during the pandemic, supporting people (including autistic people) to keep in touch with loved ones and professionals who supported them.³⁹ [Curators of Change](#) are working with Norfolk County Council to create a Real Care Deal for Norfolk, with the intention of providing a more ethical approach to how Adult Social Services works with people and providers.

Community support available to everyone has also improved, with autism social groups now being held in libraries across Norfolk.⁴⁰ These groups support autistic people to meet others, to help reduce loneliness and isolation. Information about the groups is available on the Norfolk Autism Partnership's '[What's On?](#)' webpage and in local libraries.

People have told us that much more needs to be done to improve the support available in the community. They told us that early intervention is important, to prevent people's needs from escalating. They talked about the need for ongoing support for autistic people, and improvements to social care services. And they told us about the importance of housing and independent living.

Carers of autistic people also find it hard to get the support they need. A survey of carers, carried out by Carers Voice Norfolk and Waveney during the development of the [All Age Carers Strategy](#), found that 62% of carers of autistic people had found it difficult to get the support they need. This rose to 77% for those carers who were also autistic themselves.

³⁸ [Assistive technology - Norfolk County Council](#)

³⁹ [Adult Social Care digital initiative scoops silver at prestigious national awards - Norfolk County Council](#)

⁴⁰ Data provided by Norfolk Autism Partnership Board

Our plans to achieve this priority need to reflect the [All Age Carers Strategy](#), and other local strategies which are relevant to support for autistic people in the community, such as the [Learning Disability Plan](#). We will identify where actions planned as a result of those strategies will help us to achieve the priorities within this strategy.

What is important to people

“
Life at home, relationships – support for neurodiverse spectrum couples and help to have a healthy relationship and family life.
Norfolk Resident
”

“
More support directed towards autistic adults. Not everyone will seek out the support.
Norfolk Resident
”

Early intervention

- People said that there should be more social groups for autistic people, to prevent loneliness and provide opportunities to meet others. This includes groups in smaller places as well as large towns and a mix of in person and online groups.
- People said there is a need for support to help autistic people understand themselves. This includes support with managing their own mental health and support for late diagnosed adults.
- People said that peer support would enable autistic people to support each other. A start-up pack could enable autistic people to set up new social and support groups.
- People said that parents, carers and families need more support.
- People said autistic people could benefit from support to identify and set up assistive technology (gadgets and apps that can help people to live independently).

Support for autistic people

- Many people said that a drop-in service available to all autistic people is needed. This would mean people could get occasional support when they need it. Several ideas were suggested for this, such as using hubs in the community, or a bus that travels around.

- People said that guidance about positive relationships is needed. This includes making friends, how to have healthy relationships, and awareness of scams, financial exploitation, and domestic abuse.
- People said that support is needed to manage life changes and transitions. This includes moving home, getting a new job, becoming a parent and bereavement.
- People said that it would be helpful to have one consistent person to go to. And when services are working with people, it is helpful for them to check in regularly with the autistic person.

Social care services

- People said that professionals should take a whole family approach. This includes considering siblings and their needs.
- People said that more respite options are needed to support family carers.
- People said that waiting times for allocation to a social care worker should be reduced.
- People said improvements to communication and the approach taken for an Adult Social Services assessment are needed.
- People said that more flexibility would help families to use Short Breaks funding at times that work for them, and that it can be hard to provide the evidence required to access support.

Housing and independent living

- People said that autistic people need support to develop the skills for independent living. They said that people may appear to function really well in some areas, but still need support in others. This needs to start early, but also be available throughout the life span.
- People said that more information about independent living options is needed.

6

Improve support within the criminal and youth justice system

By 2029, we want autistic people who come into contact with the criminal and youth justice system to get the support that they need. Through early intervention, we want fewer autistic people to become victims of crime or to be convicted of a crime. We also want those who have been convicted of a crime to get the additional support they may need to fully engage with their sentence and rehabilitation.

What we know nationally

Autistic people are over-represented within the criminal justice system as victims, witnesses and defendants. However, they often have poor experiences when they come into contact with the criminal justice system.⁴¹ This can be because of poor understanding of autism among professionals, and challenges with getting the reasonable adjustments they need to support them.⁴² There is also evidence that autistic people who are in contact with the criminal justice system often struggle to get the health and social care services they may need.

Research in 2017 found that 9% of a sample of prison inmates were likely to be autistic⁴³ and it is recognised that neurodivergent young people are also over-represented in the youth justice system.⁴⁴

There is evidence that autistic people are often not provided with reasonable adjustments in police stations or courts, or with an appropriate adult to support them (even when their diagnosis was known to police). When autistic people are involved in a trial, research has found that it is common for barristers, judges and magistrates to say or do something that suggests they do not have an adequate understanding of autism.⁴⁵

⁴¹ [AGGPA inquiry](#)

⁴² [Identification and support of autistic individuals within the UK Criminal Justice System: a practical approach based upon professional consensus with input from lived experience \(careknowledge.com\)](#)

⁴³ [Neurodevelopmental disorders in prison inmates](#)

⁴⁴ [Neurodiversity – a whole-child approach for youth justice \(justiceinspectors.gov.uk\)](#)

⁴⁵ [Autistic defendants are being failed by the criminal justice system | University of Cambridge](#)

What we know in Norfolk

Local data confirms that the proportion of autistic people within the criminal justice system is higher than the general population, even though the data only includes those with a diagnosis. 3% of prisoners accessing prison healthcare in the East of England region have a diagnosis of autism.⁴⁶

The three prisons in Norfolk all now have Neurodiversity Support Managers, who provide support for autistic prisoners. Autistic prisoners told us that this support is highly valued.

Norfolk Constabulary has brought in sensory boxes to support autistic people in police stations, and any autistic people in custody should see the [Liaison and Diversion Service](#) who help to identify appropriate support. This includes provision of [appropriate adults](#) to support autistic people through the process.

[Norfolk Youth Justice Service](#) (NYJS) was awarded the Youth Justice Special Educational Needs and Disability Quality Mark in February 2023, for partnerships securing better outcomes for children and young people with SEND in the youth justice system. NYJS in partnership with Norfolk Constabulary and Norfolk Children's Services operates a diversion scheme, which successfully works to divert children away from the formal criminal justice system. The NYJS health team is a multi-disciplinary team of health professionals providing support to children, families and professionals within the service.

People have told us that more needs to be done to improve support in the criminal and youth justice systems. They talked about the importance of early intervention and the need for support in police stations and courts, and in prison. They also told us about the importance of support for autistic people when they are released from prison.

What is important to people

“ More awareness and support for reoffending programmes tailored for autistic people. Ensuring probation staff are trained to stop recall being the first option when someone with autism is struggling and can instead support them better. Norfolk Resident ”

“ Some autistic people are coerced into criminal activity due to a variety of factors that is not a deliberate intention or awareness of hurting others, with lack of autism awareness from professionals. Norfolk Resident ”

⁴⁶ Data shared by NHS England (East of England)

Early intervention

- People said that the right support early on could help to prevent a situation from getting much worse. This includes how the police approach an autistic person, to make sure they ask questions in the right way.
- People said that autistic young people and adults are vulnerable to exploitation and need support to prevent this.
- People said there is a need for support to understand good citizenship and appropriate behaviour.
- People said that those who may be autistic and are subject to Community Sentence Treatment Requirements (CSTRs) need more support, to prevent them from re-offending.

Support in police stations and court

- People said there is a need for advocacy to support autistic people with communication and to help them understand what is happening. This includes the availability of [appropriate adults](#) to support autistic people in police stations.
- People said that more needs to be done to make reasonable adjustments for autistic people, particularly in courts.
- People said that autism friendly information about processes in court and police stations is needed.

Support while in prison

- People said that autistic prisoners need more support, including reasonable adjustments to make the environment more appropriate.
- People said that more support is needed for autistic prisoners to develop work skills and get a job on release.
- People said that there should be autism friendly programmes for offenders.

Support on release from prison

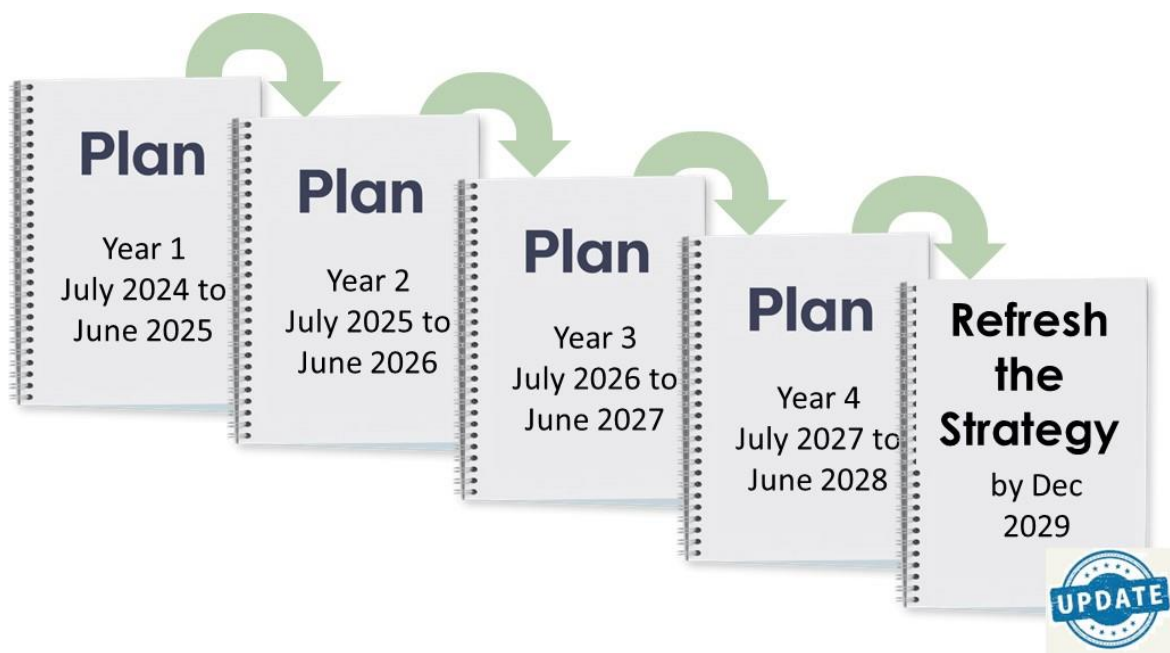
- People said that autistic prisoners need support when they leave prison. Autistic prisoners sometimes miss out on probation support due to reaching the end of their sentence through being recalled.
- People said that licence conditions should be clear and unambiguous. They said that autism friendly information in approved premises could help autistic people to understand the rules and what they can and cannot do. This could also include approved premises which are specifically for autistic people.

Making the vision a reality

This strategy should be read alongside the NAPB's strategy plan, which can be found on [their website](#). The year one plan will be developed with partner organisations from July 2024, and will be updated each year from 2025 to 2029.

The plan for each year will set out the key actions that partner organisations will take towards achieving the priorities of this strategy. The NAPB will put in place a working group which will include autistic people to oversee the development of the plan and to monitor it.

By January 2029, the NAPB will start work to refresh this strategy for 2030 onwards.



Glossary

Co-production: this is an equal relationship between people who use services and the people responsible for services. They work together, from the start to the end of a project.

Education Health and Care Plan (EHCP): a plan for a child or young person aged up to 25 who has complex special educational needs and disabilities. It sets out the support they need to achieve their best outcomes.

Easy Read: a way of making written information easier to understand by using simple language and illustrating the information with pictures.

Healthwatch: a statutory agency whose role is to monitor NHS services on behalf of the public and make its findings public.

Independent advocacy: independent advocates support people to speak up for themselves or give their views. They are independent because they do not work for the organisations that they are supporting people to talk to.

Integrated Care System: integrated care systems were set up by the Health and Care Act 2022. The [Norfolk and Waveney Integrated Care System](#) is a partnership of local health and social care organisations.

Kitemark scheme: an official scheme which awards a mark of quality and reliability to organisations which meet a required standard.

National Institute for Health and Care Excellence (NICE): this organisation provides evidence based recommendations for the health and social care sector, developed by independent committees.

Norfolk Autism Partnership (NAP): a partnership of autistic people, parents, carers, voluntary and statutory organisations working together to achieve an autism-friendly Norfolk. More information is available on the NAP's website: [Home - Norfolk Autism Partnership](#).

Norfolk Autism Partnership Board (NAPB): the Board which manages the Norfolk Autism Partnership. Members of the Board include autistic people, parents/carers and representatives of voluntary and statutory organisations in Norfolk. The Board meets every two months.

Preparing for Adult Life (PfAL) team: this team is responsible for ensuring young people make a smooth transition into Adult Social Services. They work with young people who are likely to need support from Adult Social Services when they turn 18.

Reasonable adjustments: the Equality Act (2010) requires employers, businesses and service providers to make reasonable adjustments so that their services are accessible to everyone. For example, by being flexible about appointment times, or providing a quiet place to wait.

Special Educational Needs and Disabilities (SEND): usually used in the context of children and young people up to the age of 25 years.

Specialist Resource Base (SRB): these provide children and young people with the extra support they need within a mainstream school. [Autism SRBs](#) are specifically for autistic children and young people.