

2024 - 2029



HEREFORDSHIRE AND WORCESTERSHIRE

All-Age Autism Strategy

“
Strengths of
Autistic People need
championing, support
with barriers but promote
their brilliance!!!
”



Introduction from Herefordshire and Worcestershire Autism Champion

Welcome to Herefordshire and Worcestershire's All Age Autism Strategy, which has been thoroughly co-produced across both Herefordshire and Worcestershire Autism Partnership Boards.

We have been passionate in our commitment to getting the real-life experiences of autistic people and co-producing something practical and meaningful. This strategy is for and about people of any age, with a formal diagnosis of autism, as well as those who identify as autistic. It aims to look at how we can overcome existing barriers whilst also promoting what autistic people have to offer.

To develop this strategy, we talked to autistic people, family carers, people who work in support services and anyone else living in our communities with an interest in autism.

We ran workshops, facilitated groups and conducted a questionnaire. We wanted to hear as many autistic views as possible, so we spoke directly to as many people as we could.

There is a National Autism Strategy, so we also looked how we can implement this across our two counties.

[The national strategy for autistic children, young people and adults: 2021 to 2026 - GOV. UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/national-autism-strategy)





Bernadette Louise
Integrated Care System
Autism Champion

“
I have a strong vision
of what is needed
to best support
autistic people in
our community
”

Quote from Bernadette Louise, Integrated Care System Autism Champion:

“As the ICS Autism Champion, I offer the autistic viewpoint to high level discussions. As a professional, autistic person and family carer, I have a strong vision of what is needed to best support autistic people in our community.

As it happens, lots of the people we co-produced with had similar and varied life experiences, with equally strong opinions. I believe that in this strategy we have pulled together many of the aspects in life, that we have daily challenges with.

I expect this strategy to provide us with the platform we need to not only elevate the profile of autism, but also see significant and meaningful change.

It should enable the system to support us without barriers, discrimination and with empathy and knowledge. I expect this strategy to hold weight and allow accountability so we can look back on the two counties and see real-life progression over time.”

About Autism

Autism is a lifelong developmental condition that affects how people communicate and interact with the world.

Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. Remember - if you have met one autistic person, you have met one autistic person. Autistic people will not look or present in the same way. Some autistic people will have a formal diagnosis, some people identify as autistic with no formal diagnosis, others will not be aware of their autism. You can find out more about autism diagnosis on the National Autistic Society website: [Diagnostic criteria \(autism.org.uk\)](https://www.autism.org.uk).

While autism is not a learning disability, [around 4 in 10 autistic people have a learning disability \(Autistica\)](#). We also have learning disability strategies for [Herefordshire](#) and [Worcestershire](#).

Autism is not a mental health problem but, like everyone else, autistic people can have good and bad mental health. Anxiety and depression are particularly common in autistic people, possibly due to difficulties with how to interact in a neurotypical world. The National Autistic Society has Autism and Mental Health Pages: [Mental health \(autism.org.uk\)](#).

More than 1 in 100 people are on the autism spectrum and there are more than 700,000 autistic adults and children in the UK, taken from: [What is autism \(National Autistic Society\)](#). It is likely that the true autistic population is much higher due to lack of awareness, the wait for diagnosis and national recording systems.

“
An autistic person is first and foremost an individual, so no two people will have the exact same experiences... so each person must be seen holistically.
”

As part of this strategy, we are going to collect people's experiences in Herefordshire and Worcestershire. There are also a series of podcasts created by Worcestershire Children First with school age children describing their experiences: [Mind-boggling Conversations - YouTube](#).

You can also view experiences collected by the National Autistic Society on their webpage: [Stories from the spectrum \(autism.org.uk\)](#).



1 in 100
people are on the
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Strategic Context

This Strategy has been developed in the context of the Herefordshire and Worcestershire Integrated Care Strategy 2023-2033 “Good Health and Wellbeing for Everyone”, with a particular focus on tackling inequalities in terms of outcomes, experiences, and access.

It also links to and supports numerous strategies across the integrated care system for children, young people and adults, including, but not exclusively, those relating to Prevention (including Suicide Prevention), Children and Adult Social Care and Special Educational Needs and Disabilities.

Our Vision in Themes

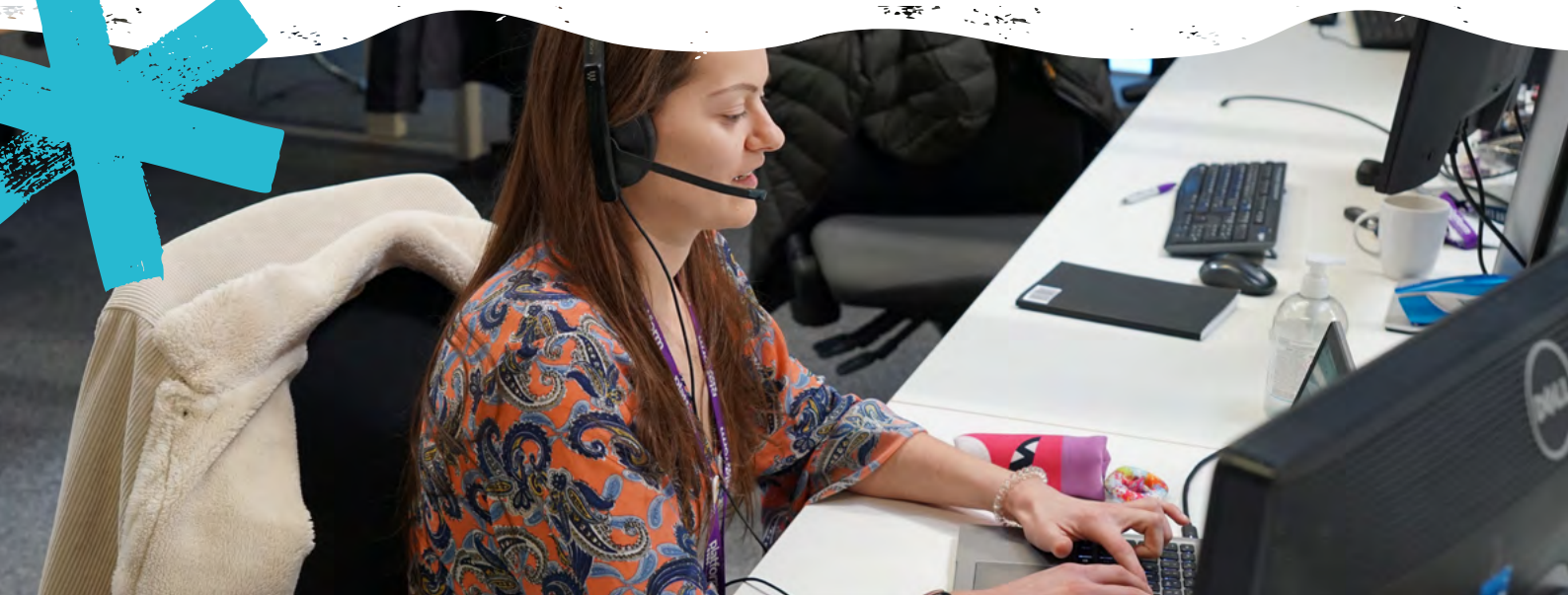
Our Partnership Boards agreed the strategy should focus on the priorities within the National Strategy, with an additional priority around keeping safe. This is the vision for each of our themes:

Improving understanding and acceptance of autism within society

We want to demonstrate that we have significantly improved public understanding and acceptance of autism, and that autistic people feel more included in their communities and less lonely and/or isolated. We want the public to have a better understanding of autism and to have changed their behaviour positively towards autistic people and their families.

Improving autistic children and young people's access into education and support positive transitions into adulthood

We want education settings to provide better and more inclusive support to autistic children and young people so that autistic people are better able to achieve their potential. We want more teachers and educational staff to understand the specific needs of their autistic pupils, ensuring that more school placements can be sustained. We also want to demonstrate that more autistic children have had their needs identified early on and that they are having positive experiences in educational settings. We want to ensure that we make improvements to support and prepare autistic children and young people for transition to adulthood to enable them to reach their full potential.





Supporting more autistic people into employment

We want to make progress on closing the employment gap for autistic people. We want more autistic people who can and want to work to do so, and to ensure that those who have found a job are less likely to fall out of work. We also want to show that employers have become more confident in hiring and supporting autistic people, and that autistic people's experience of being in work has improved.

Tackling health and care inequalities for autistic people

We want to reduce the health and care inequalities that autistic people face throughout their lives, and to show that autistic people are living healthier and longer lives, ensuring timely access to needs-led health care. In addition, to have made significant progress on improving early identification, reducing diagnostic waiting times, improving diagnostic pathways and access to mental health support for children and adults, so autistic people can access a timely diagnosis and the support they may need across their lives.

Building the right support in the community

We want all autistic people to have the opportunity to participate in their communities among friends and family. Autistic people should live in their own home or with people they choose to live with. We are clear that people should not be in inpatient mental health settings unless absolutely necessary for clinical reasons and will focus on providing good support at the right time to reduce incidence of crisis.

Improving support in criminal and youth justice systems

We want to have made improvements in autistic people's experiences of coming into contact with the criminal and youth justice systems, by ensuring that all staff understand autism and how to support autistic people. We want all parts of the criminal and youth justice systems, from the police to prisons, to have made demonstrable progress in ensuring that autistic people have equal access to care and support where needed. In addition, we want autistic people who have been convicted of a crime to be able to get the additional support they may require to engage fully in their sentence and rehabilitation.

Keeping safe

We want to enable autistic people to feel empowered to keep themselves safe in the community; have a better and safer experience of everyday life and be well supported by services that help them feel safe and secure.

“

An autistic person is first and foremost an individual, so no two people will have the exact same experiences... so each person must be seen holistically.

”

Cross cutting themes



Our work on the strategy has also identified some themes that cut across many of these priorities.

Public perception of autistic people

We want to demonstrate that we have significantly improved public understanding and acceptance of autism and have good quality local resources to share. We have set out aims and actions around this in priority 1 but people talked about this in each priority.

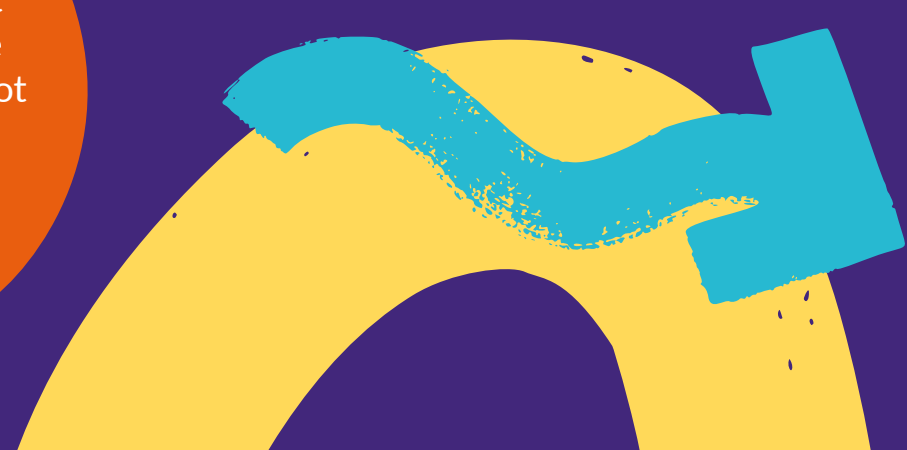
Many autistic people need support/advocacy to access mainstream services or navigate systems. Carers are worried there will be no support for their autistic child when they can no longer provide it

The need for support was clearly evidenced through work on all of the priorities and for people of all ages and their carers. We want to continue the multi-agency approach taken with this strategy to plan the best way for people to get the support that they need.

“

Autistic people...do not know how they will live when their parents cannot help them. Someone needs to help them.

”



Some autistic people are not getting the right support for their mental health needs

We have set our aims and actions around this in priority 4 but people talked about this in each priority. Many people talked about feeling suicidal because of their situation. Autistic people are at a higher risk of suicide than non-autistic people. Figures show that as many as 11-66% of autistic adults had thought about suicide during their lifetime, and up to 35% had planned or attempted suicide (Hedley, D., & Uljarević, M. 2018). We want to use this strategy to tackle issues facing autistic people in Herefordshire and Worcestershire to improve mental health and wellbeing and to reduce the risk of suicide and suicidal thoughts. We want to explore opportunities for autistic people to feel connected to their local community, working to reduce isolation and loneliness. By providing opportunities to socialise and promote a sense of belonging and safety through a wide range of opportunities, we can work together with our partners to improve autistic people's wellbeing and prevent suicide. The Autism Partnership Boards are working closely with the Herefordshire and Worcestershire Suicide Prevention Partnerships in order to achieve these aims.

Autistic people, particularly but not exclusively women and girls, are "masking" as an approach to fit in to a non-autistic culture

Masking or camouflaging is where an autistic person hides their autistic traits and/or behaviours in certain social situations to better fit in with those around them. We want to use this strategy to improve understanding of autism and the different ways people present, developing a culture of acceptance and understanding where autistic people do not feel pressurised to hide who they are. We want to educate organisations about masking, so that we can improve the mental health and wellbeing of those who mask, as well as the families and carers who are supporting the exhaustion and burn out of a person who is masking.

Organisations need to make reasonable adjustments

We want to promote good practice examples of reasonable adjustments to all organisations in Herefordshire and Worcestershire and remind organisations of their duties under the Equality Act 2010 and the Autism Act 2009.

“

My daughter masks so well that others find it hard to accept [that she is autistic]. There is little understanding of how exhausting masking can be.

”



Reading and using this Strategy

For each priority we have set out what we know, our high-level aims, and key actions.

We would like organisations in Herefordshire and Worcestershire to use these aims and actions in their own individual strategies and delivery plans so that together we are creating a great place to live for autistic people.

We hope you enjoy reading our strategy! We will issue regular newsletters setting out progress on our strategy.

How will we monitor this strategy?

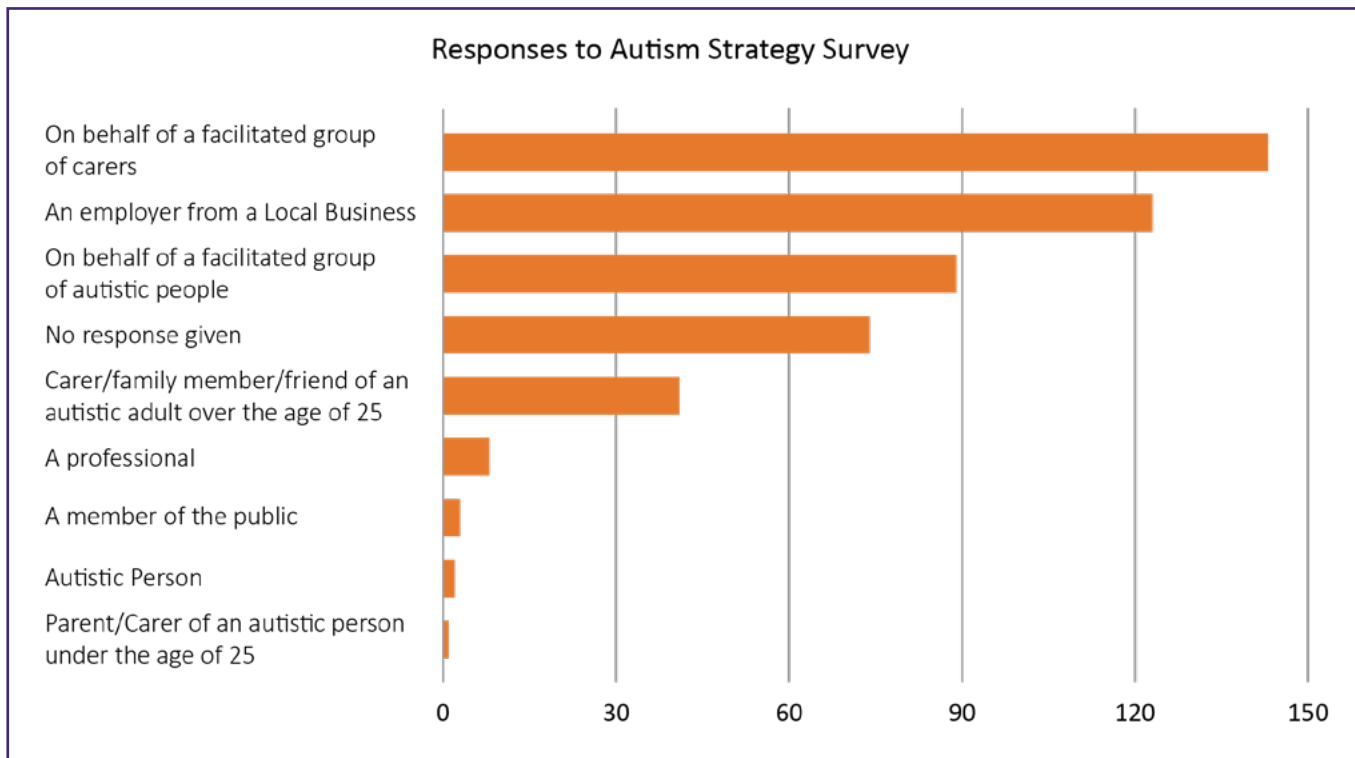
There is an identified lead for each priority who will work with partners, including autistic people and their families, to oversee the actions agreed. An annual action plan will be produced for each priority setting out areas of focus and how we will monitor success. Over the course of the strategy these workstreams may identify additional aims and actions, particularly if a new National Autism Strategy is produced.

Progress will be discussed at Autism Partnership Boards and reported to the Integrated Care System (ICS) Developing Services for Autistic People Programme Board. An annual report will be taken to the Health and Wellbeing Boards in both counties. A bi-annual newsletter will be produced to keep everyone updated on progress.

Who was involved?

Autism Partnership Boards in both Herefordshire and Worcestershire (made up of people with lived experience, carers, health and social care professionals, representatives from the charitable, voluntary, provider and statutory organisations) co-produced a plan for the content of the strategy and the strategy engagement plan. A whole population survey was conducted across both Herefordshire and Worcestershire in March 2023, receiving 442 responses from a wide range of people.





*Please note, respondents were able to tick more than one box for this question with carers and professionals also ticking autistic person.

A designated lead for each priority, led focus groups and meetings to discuss the findings from the engagement and co-produce high level aims and key actions.

We are proud of the co-production on this strategy. However, we know there are still many autistic people and families that we did not reach and we will strive to further increase engagement in action plans and delivery of the strategy.

Herefordshire

Estimated population of autistic people in Herefordshire calculated at 1.1% of resident population				
	2020	2025	2030	2035
Total Population	2,120	2,170	2,210	2,230
Total Population - Children and Young People	400	410	400	390
Total Population - Adults	1,720	1,760	1,810	1,840



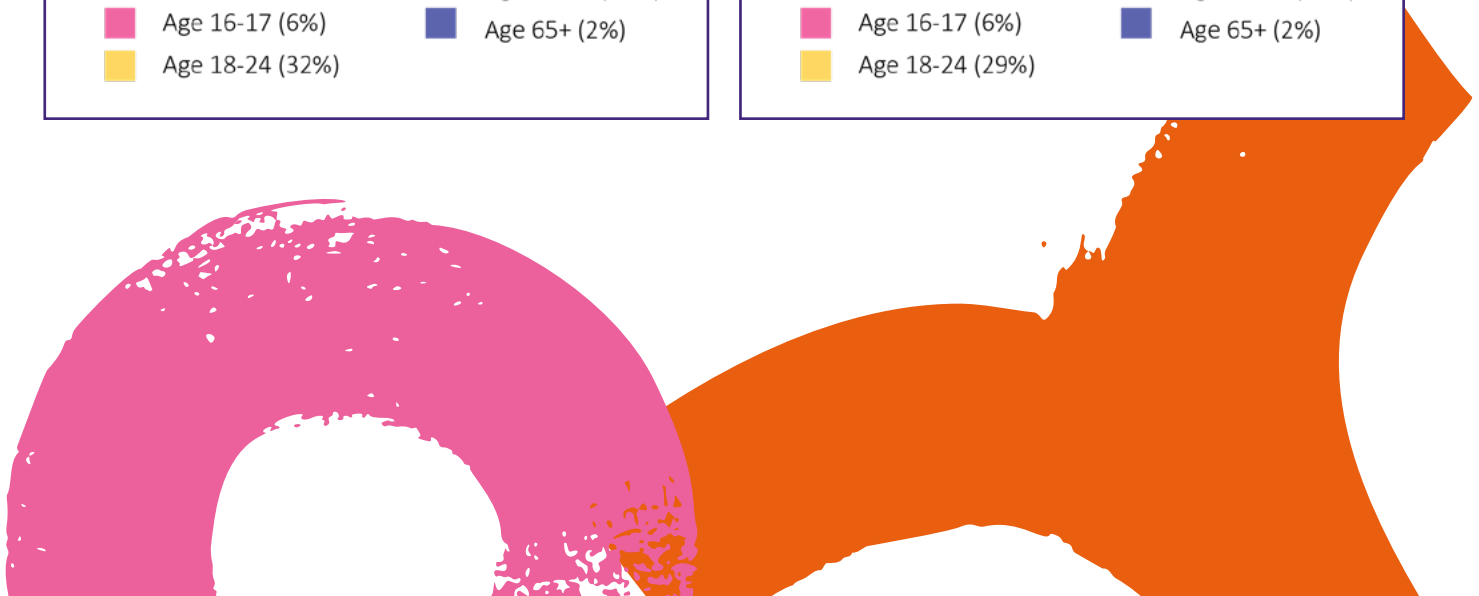
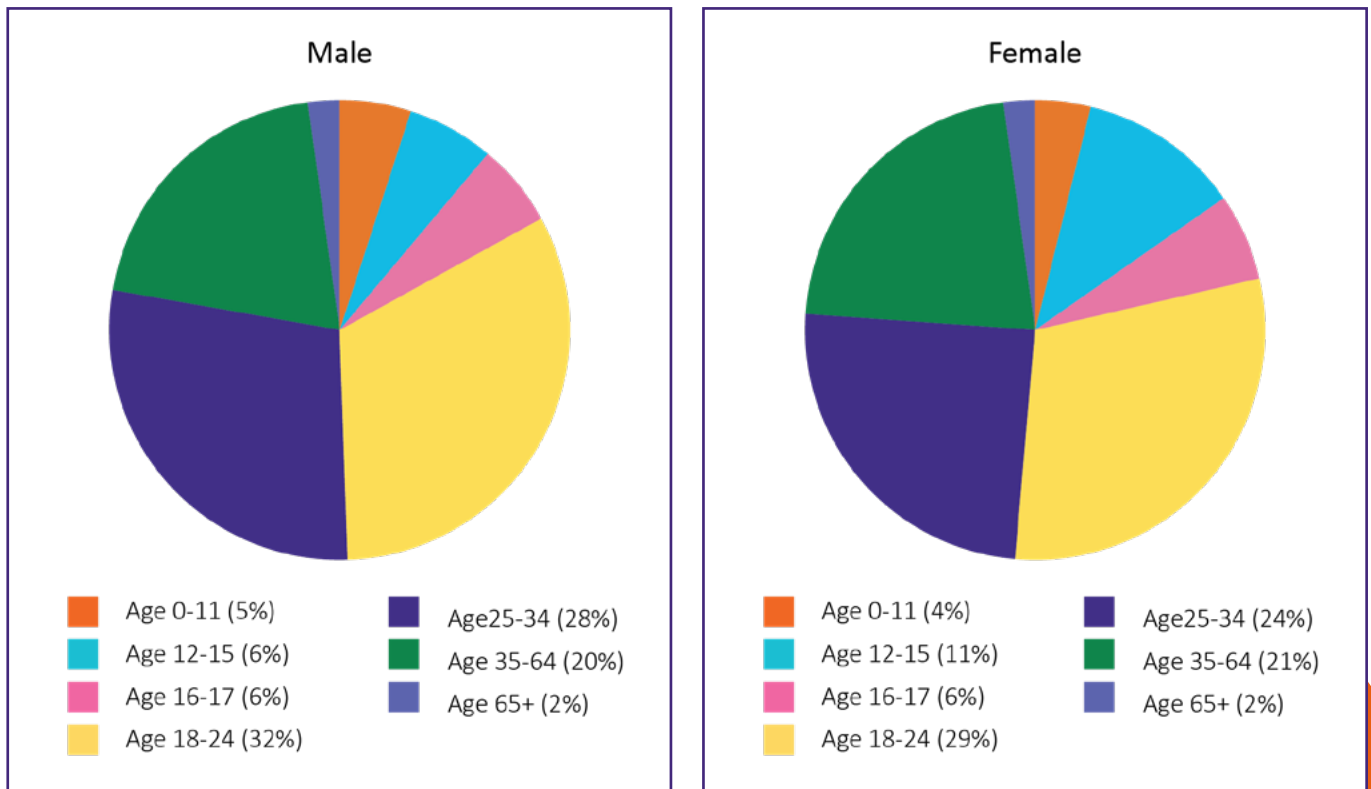
Worcestershire

Estimated population of autistic people in Worcestershire calculated at 1.1% of resident population				
	2020	2025	2030	2035
Total Population	6,550	6,690	6,830	6,940
Total Population - Children and Young People	1,310	1,330	1,330	1,320
Total Population - Adults	5,240	5,360	5,500	5,620

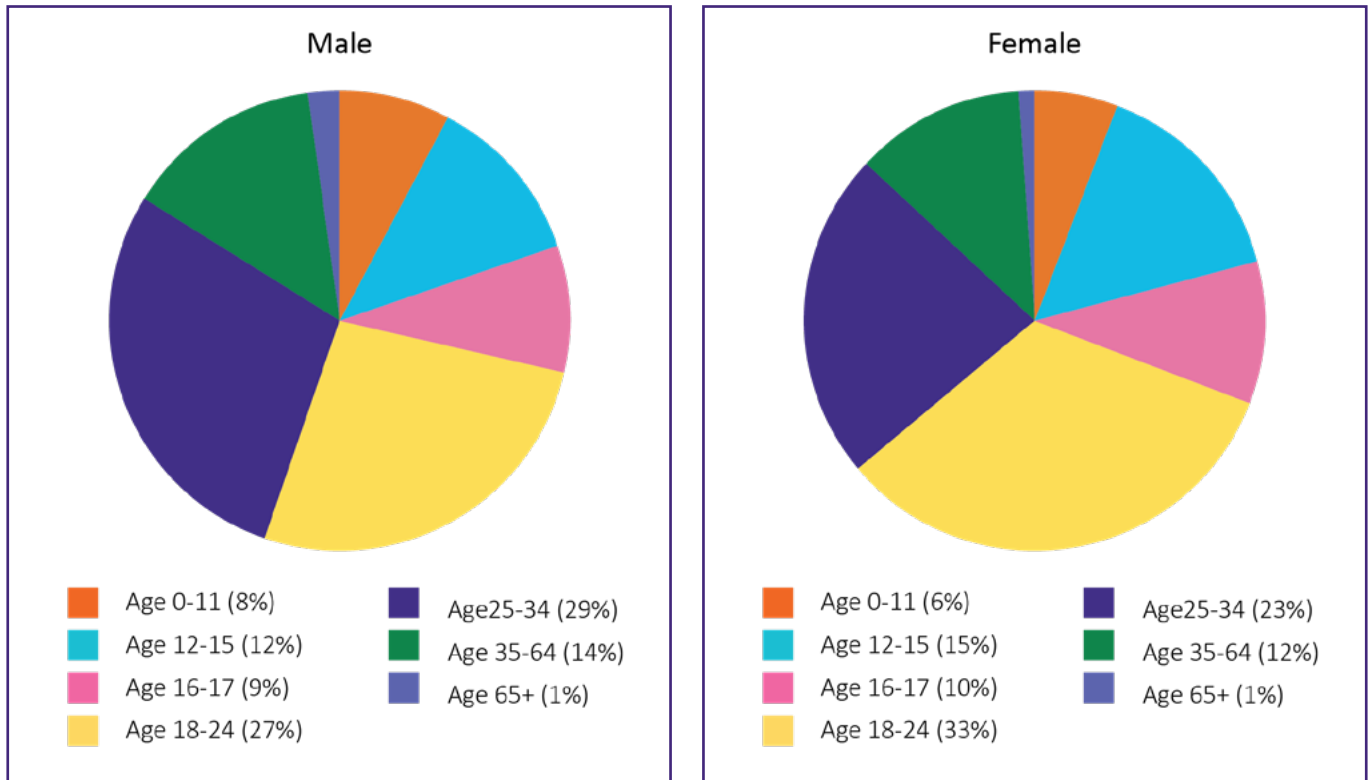
A review of our primary care data shows that in comparison with the national estimates of prevalence, only 40% of autistic people are currently recorded on the health system in Worcestershire and 29% in Herefordshire. This is likely to change over the lifespan of this strategy with national changes in NHS record systems. It is also worth noting that national prevalence data is likely to be an underestimate. Data in the United States is now showing that 1 in 36 children have autism: [Autism Statistics and Facts](#) | [Autism Speaks](#).

The tables below show the mix of sex and age within the autistic people recorded.

In Herefordshire:



In Worcestershire:



Over 90% of the individuals recorded are White British in both counties.

In Worcestershire, there are currently 294 autistic people known to adult social care where autism is recorded. Of these, 186 people also have a learning disability. Autism is not a specific category on the social care system so the actual numbers are likely to be higher.

As of the end of August 2023 (latest data) there are 1,176 Children with an Education Health and Care Plan (EHCP) and a primary need of autism in Worcestershire: 21% of children with an EHCP.

There are 503 carers known to Worcestershire's Carers Hub who are supporting an autistic person.

In Herefordshire

As of the end of August 2023 there were 1,463 children and young people with an Education Health and Care Plan maintained by Herefordshire 0-25 years of which 325 were recorded with a primary need of autism: 22% of children with an EHCP. This is significantly lower than national average and is thought to reflect the length of waiting list for a diagnosis of autism. Work is being done to update local authority records and improve accuracy.



Priority One: Improving understanding and acceptance of autism within society.

“

Understanding what autism is and that each person with a diagnosis is impacted on in different ways and in different scenarios. Just not assuming they are being difficult or awkward.

”

What do we know?

94% of respondents to our questionnaire felt that the general public had a poor understanding of autism.

Autistic people told us about experiences in shops and public spaces. Some people welcomed quiet hours or specific autism events. However, the majority of people said staff working in shops and local services needed to have more understanding (through training) and empathy. They particularly need more awareness of sensory overload in public settings.

44% of autistic people had experienced barriers on public transport describing issues with noise, sensory overload and timetabling issues.

High Level Aims

- Everyone, including people who work in local shops, services and public transport should understand and accept autistic people, make sure they are included and treated with respect.
- Local organisations who provide services to the public should make reasonable adjustments, as set out in the Equality Act 2010 and the Autism Act 2009. These adjustments include ensuring that staff have appropriate training.

Key Actions

- Production and promotion of local autism resources to promote understanding and acceptance. To include voice recordings of autistic people describing experiences, posters, social media.
- Increase availability of autism training for people working in customer facing roles.
- Development of a sensory/autism audit tool for shops/public buildings and material explaining the need for a quiet hour.
- Engagement with local retailers to agree how to work together.
- Engagement with local transport services to agree how to work together.
- Development of a sensory/autism audit tool and autism material for local bus services.

“

There is a real lack of positive images and stories of autistic people coping and enjoying fulfilling lives.

”



Priority Two: Improving autistic children and young people's access into education and support positive transitions into adulthood.



Herefordshire

What do we know?

New mainstream autism bases have recently opened, delivering 42 additional specialist placements locally. These are already demonstrating a positive impact on attendance, engagement and learning. However, there is still insufficient local provision: 21.8% of pupils with an Education Health and Care Plan (EHCP) placed outside the state funded school and college sector have a primary need of autism. Autism remains a priority for special educational needs planning; both to respond to further increases in requirement, and to support children through phases of education and into adulthood.

50% of schools have accessed the West Midlands autism training and there is an improved early years' offer. However, parents remain concerned for their children and this is reflected in the higher numbers of requests for EHC assessments in recent years. Feedback from the questionnaire demonstrated a lack of confidence in the targeted schools offer. Some autistic children and young people are still having poor experiences within school, are not reaching their potential and are struggling in the transition to adult life. Anxiety and other mental health concerns in children has increased in combination with neuro-diversity related needs since the Covid Pandemic; this is reflected in the profile of the more recent EHCP cohort.

Children and young people with autism often experience high levels of anxiety in school which places them at greater risk of Emotionally Based School Avoidance (EBSA). Frequent sensory processing differences can make the world unpredictable for autistic children and young people. Stressful sensory experiences can heighten this anxiety for autistic children and young people in educational settings: this can include busy corridors, colourful displays and school uniforms in materials that they might find difficult to tolerate. Sometimes behaviour caused by sensory and emotional distress can be confused with disobedience. This can result in autistic children and young people being particularly vulnerable to being excluded from school. To avoid this risk and reduce the long-term harm resulting from high levels of anxiety and sensory distress, parents may exercise their right to educate their autistic child at home.

We want to ensure that improvements are made to support and prepare autistic children and young people for transition to adulthood which allows them to reach their full potential. This success is dependent on autistic children having more settled, happy and comfortable experiences throughout their primary and secondary phases of education.

High Level Aims

- To ensure that all children and young people (including autistic children and young people) feel safe, loved and valued, and grow up with the confidence and skills to be the best they can be.
- An area wide accreditation and quality standards system and campaign for education and community settings.
- A “looking to my future plan” is in place and working from the earliest point so that transition and preparation for adulthood planning is part of the team around the child discussions from an early age.
- Parents and young people’s views and experiences shape all that we do so that resources are developed and targeted as effectively and efficiently as possible.
- Effective multi-agency early identification and pathways for support ensure that early and timely help addresses needs well.
- Sustainable and sufficient educational provision in mainstream and specialist settings ensures a local education offer for other than exceptional circumstances.
- Recruit and retain confident and skilled workforce so that the local education offer is viable and sustainable.



Key Actions

- To work with schools, early years and colleges to plan for workforce support and training and a network of professional opportunities across the area.
 - To work with our SENCo network to map best practice in education across Herefordshire.
 - To work with health, early help and early years settings to ensure a coordinated and effective pathway.
 - To establish sufficient local educational placements and provision for children and young people with a primary need of autism so that the right child and the right provision is in place from the earliest point.
 - To map community groups/organisations for children and young people across Herefordshire and use the map to improve links with local schools so that there are more schools and colleges who have a broader programme of community groups coming into the learning environment.
 - To introduce a more comprehensive pathway to accreditation (autism quality mark) for education settings, staff and community providers.
 - Schools to invite community groups in to build skills and confidence in the young people to try new groups and activities.
 - To develop an area strategy and campaign to recruit support staff using young people's voices and case studies and other incentives to address recruitment and retention issues across the system.
 - A passion for what autism inclusive looks like to include an area wide programme of events for autism acceptance week.
 - There will be an expectation of a transition plan started and a named worker identified to facilitate that plan, from the earliest age. Others who are important to the child and to support the facilitator will be identified and share responsibility for the success of the plan.
 - A resource bank of information and case studies will be available to support transition planning from the earliest age.
 - The transition plan will focus on opportunities, experience and skill development to build confidence, self-advocacy and informed choice.
 - A safety net approach will be in place to support young people who are at risk of self-excluding from a workplace when they first encounter barriers they see as insurmountable.
 - All EHCP annual reviews to have a section on planning for my future including how I would like to/am accessing community activities.
 - Specific guidance and support for inclusion of young people with autism in educational activities in personal and social education.
 - Additional resources and support will be available to support young people with autism who need more personalised help with puberty and relationships.
 - Link to existing workstreams to change and improve parent and young people's experience of meetings and planning with practitioners.
 - Co-produce an accessible training module on reasonable adjustments for all education and community providers.
 - Co-produce a more robust proforma/process for capturing parent views in the EHCP statutory processes.
 - Multi-agency workshops co-facilitated by parents on personally appropriate outcomes for children and young people with autism.
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Worcestershire

What do we know?

A growing number of children and young people are being diagnosed as autistic.

Some autistic children and young people are still having poor experiences within school, are not reaching their potential and are struggling in the transition to adult life.

Some autistic children find school environments overwhelming and evidence from the All-Party Parliamentary Group on Autism (APPGA) shows they often feel misunderstood or judged by their peers because of their behaviour, which can impact their ability to engage and succeed in education.

Children and young people with autism often face additional challenges in school which may make them anxious and experience Emotionally Based School Avoidance (EBSA). Frequent sensory processing differences can make the world unpredictable for autistic children and young people. Sensory experience can impact on the anxiety of autistic children and young people in an educational setting, this can include busy corridors, colourful displays to school uniforms in materials that they might find difficult to tolerate.

Sometimes behaviour associated with their autism can be confused with disobedience. This can result in autistic children and young people being particularly vulnerable to being excluded from school. As a result of this, parents may choose and have a right to educate their autistic child at home. This can be for various reasons including the child having sensory needs that make a school environment noisy, distracting or even painful to them.

It is also widely accepted that girls are often overlooked for an autism assessment or are commonly mis-diagnosed. It is known that autism often presents differently in girls and women and that the ability to mask and camouflage difficulties results in professionals missing identifiers.

Of the 5,737 Education Health and Care Plans (EHCP) at the end of September 2023 maintained by Worcestershire, 1,216 children and young people have a primary need of autism (21.1%).

Since 2016 we have seen an increase year on year of those children and young people that are receiving SEN support at school or have an EHCP who have a diagnosis of autism.

A priority of the Worcestershire Strategy for children and young people with SEND 2023-2026 is to ensure that children and young people with autism achieve positive outcomes and the support required to enable this is in place.



High Level Aims

- To ensure that all children and young people with autism are truly seen and respected as individuals and are supported to be the best they can be.
- To assess and meet the needs of children and young people with autism, through the Graduated Response and Education Health and Care Needs Assessment for those who need it.
- Provide support and services that effectively meet needs and improves outcomes.
- To listen and work with children and young people with autism and their families to further improve and develop the delivery of support and services.
- To ensure we have effective provision which is timely.
- To strengthen the links between our approaches to early help and those children and young people to improve our identification and assessment of need.
- To ensure that transition points for children and young people are understood and smooth.
- To monitor and improve the waiting times for professional assessments.
- To develop the workforce.
- To increase supported internship and employment opportunities.

Key Actions

- Ensure that we better understand and overcome the barriers to children and young people with autism achieving good outcomes as active participants in their education.
- Engagement of parents/carers/children and young people in the multi-agency early help offers of help and support.
- Improving and clarifying the intervention pathway for children and young people with autism and emotional health and wellbeing needs across universal, targeted and specialist services.
- Working with schools and settings to support them to achieve the Autism Friendly Schools Standard to ensure they have a whole school approach to children and young people with autism.
- Ensure clear and effective support for early childhood diagnosis and support.
- Opening of the Free School in Malvern.



Priority Three: Supporting more autistic people into employment



What do we know?

Evidence shows that there is currently a significant employment gap for autistic people. Data published by the Office for National Statistics for the first time in February 2021 shows that as of December 2020, 22% of autistic people aged 16 to 64 are in employment, in contrast to 52% of people with other disabilities, and 81% of non-disabled people. The National Autism Strategy outlines that there are many factors contributing to this gap, including struggling to get a job because

of recruitment processes not being autism-friendly or difficulty accessing the support people might need to get into work or while in work.

Our local data showed that although many people did not experience work related barriers and some positive examples were shared with us, around 40% of respondents had experienced issues with all of the areas we asked about as follows:

Have you or the people you know/work with/support experienced any barriers or challenges with the following tasks?

	Yes	No	Not applicable
Applying for benefits	94 (44%)	38 (18%)	84 (39%)
Searching for jobs	82 (39%)	38 (18%)	88 (42%)
Applying for jobs	87 (42%)	30 (14%)	90 (43%)
Going for job interviews	91 (44%)	22 (11%)	94 (45%)
Starting a new job	82 (40%)	22 (11%)	100 (49%)
Working with colleagues	91 (44%)	23 (11%)	95 (45%)
Getting support needed at work	85 (41%)	29 (14%)	95 (45%)
Getting reasonable adjustments needed at work	81 (39%)	28 (14%)	98 (47%)
Other (please specify)	16 (14%)	13 (12%)	83 (74%)

*Please note, not all respondents answered all questions.

“

My son has never had the opportunity to work, or even apply and be interviewed for work. He is facing a lifetime on benefits which is also a challenge to apply for and maintain eligibility.

”

A number of people also talked about their concerns about whether the person they care for would ever be able to enter the workplace. Also highlighted was the importance for the need for a diagnosis before they could access support into the workplace.

The people we engaged with were clear that there needed to be greater understanding of autism amongst employers.

High level Aims

- Local employers and employees should better understand the strengths of and challenges facing autistic people.
- Local employers should make reasonable adjustments, as set out in the Equality Act 2010 and the Autism Act 2009. Including ensuring that staff have appropriate training.
- Autistic people should be able to access support if required for recruitment and retention.
- Autistic people should be able to access support and information regarding self-employment.

Key Actions

- Drive improved employer awareness of autism across Herefordshire and Worcestershire.
- Promote better understanding of the benefits of employing autistic people.
- Promote use of Access to Work.
- Improve understanding and reduce the stigma faced by autistic employees from work colleagues.
- Encourage employers to provide coach/buddy/mentor support through the recruitment process and when in work.
- Encourage employers to provide clear information on the recruitment process and the expectations of the job.
- Raise awareness and provide information to support employers to make the adjustments needed to recruit and properly support autistic employees.
- Promote support and information around self-employment for autistic people.
- Promote mentorship and improve access to employment support programmes.
- Lead by example across Integrated Care System (ICS) organisations by employing autistic people and having good quality HR policies for neuro-diverse inclusion.

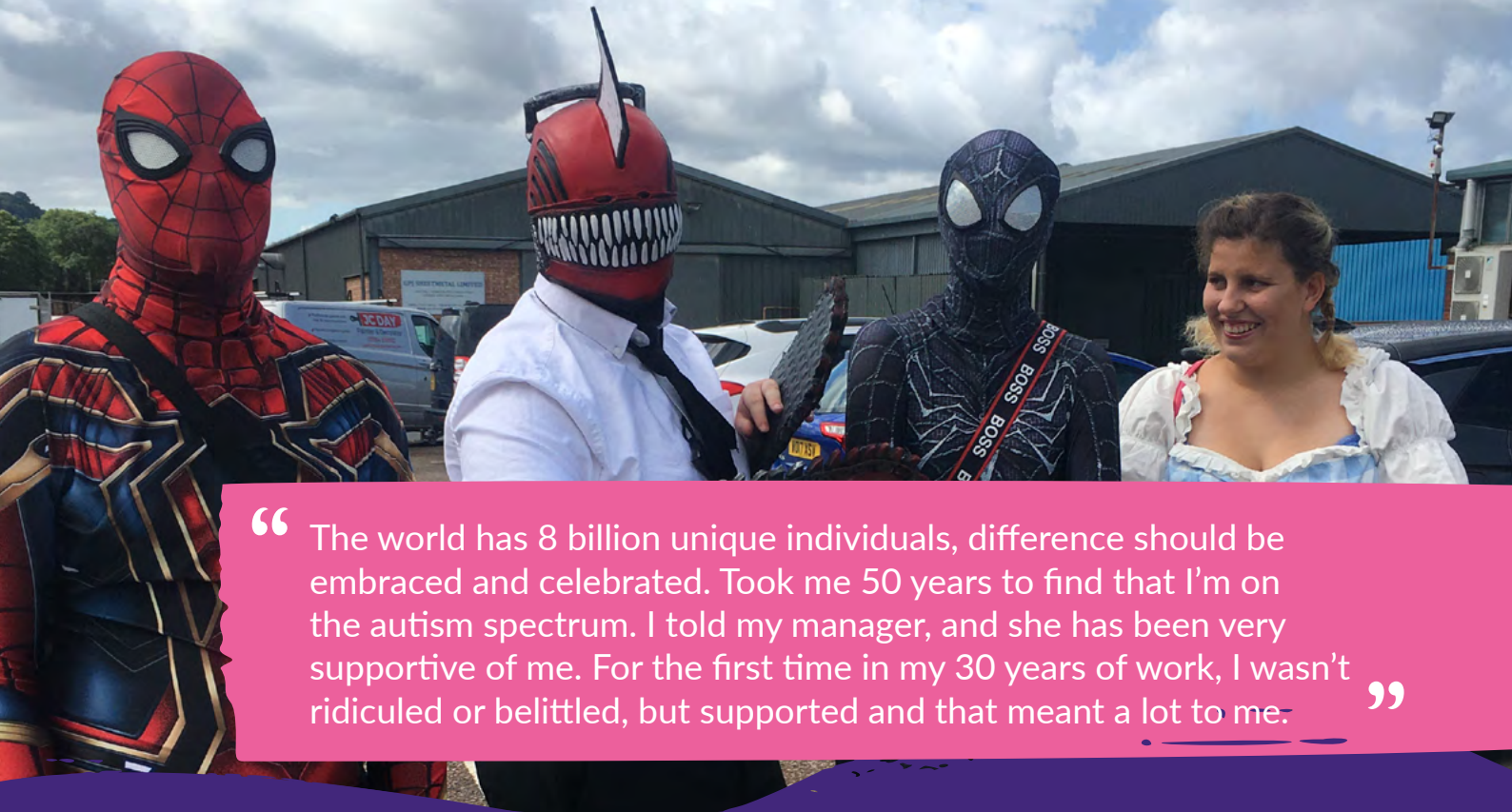
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People tend to assume all autistic people aren't literate, capable or very bright. When the spectrum is so wide, there are many super intelligent autistic people, very capable.

”



Priority Four: Tackling health and care inequalities for autistic people.



“ The world has 8 billion unique individuals, difference should be embraced and celebrated. Took me 50 years to find that I’m on the autism spectrum. I told my manager, and she has been very supportive of me. For the first time in my 30 years of work, I wasn’t ridiculed or belittled, but supported and that meant a lot to me. ”

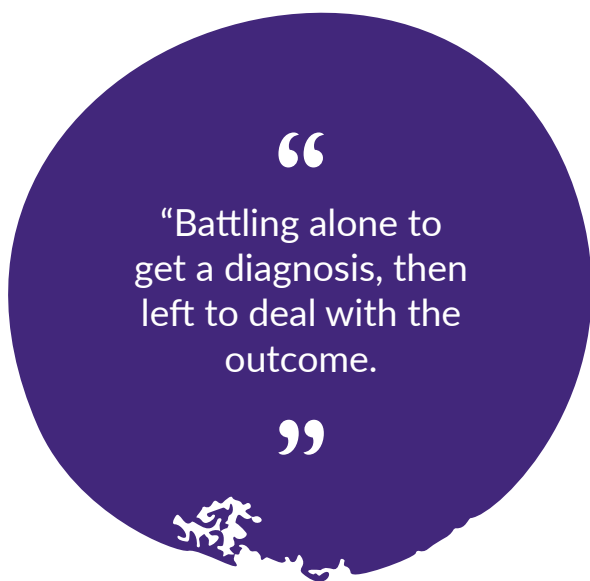
What do we know?

- Growing understanding about autism has led to a recent increase in demand for autism diagnostic assessments which currently exceeds capacity and has led to long waiting lists for children and adults.
- 0.4% of the GP registered population is recorded as autistic in Herefordshire and Worcestershire.
- 23% of people recorded as autistic also have a learning disability.
- It is estimated that autistic people have up to 16 years less life expectancy than the general population (Hirvikoski, 2015). The Herefordshire and Worcestershire LeDeR strategy established a mortality review process to enable services to learn from the lives and deaths of people with a learning disability and/or autism and make service improvements to address barriers or gaps in care.
- Almost 80% of adults and 70% of children with autism will experience a mental health difficulty, 41% will have at least two or more illnesses together such as anxiety or depression ([Simonoff, et al., 2008](#)).
- Young people with autism are at increased risk of suicidality ([Gadow et al., 2012](#); [Mayes et al., 2013](#)). 70% of young people experience suicidal ideation and 1 in 10 attempts suicide ([O’Halloran et al., 2022](#)).
- 34.2% of autistic people had experienced suicidal ideation, 21.9% had made suicide plans and 24.3% had actively made suicide attempts or demonstrated suicidal behaviours ([Newell et al., 2023](#)).

What local people told us

Autistic people and their carers often find it difficult to access health services due to concerns about different parts of the process. This included: anxiety created by communication prior to and during health appointments; environments and procedures being overwhelming due to sensory issues; uncertainty about what will happen in appointments; and/or how long they will be waiting to access a service/assessment. Whilst there were some examples of good experiences, for the majority of respondents accessing health services was very challenging. There was a strong sense that health professionals require better training to meet the needs of autistic people with 68% of respondents feeling that staff in doctors' surgeries and hospitals do not have enough training to understand and support autistic people.

Specific areas were identified which need significant improvements such as: reducing waiting times from autism diagnostic assessments and a lack of support for people waiting for and receiving a diagnosis of autism. A recurring theme from people involved in this process was that they were:



Difficulty in accessing mental health services also came through strongly. The following quote illustrates some of the key issues:



Long waiting times were highlighted as unsuitable for a person in crisis whose mental health may deteriorate while they wait for a service. Thresholds to access services were reported as too high to get support or in many cases mental health support was declined because the person had autism and difficulties were attributed to this rather than mental health. Often when people did have access to mental health support, interventions were not adapted to meet the individual needs of autistic patients (with traditional therapies such as group sessions and CBT being unsuitable for autistic people). Significant work is therefore required to improve the accessibility of mental health services and the appropriateness of treatments for autistic people.

Specific feedback from parents of children and young people identified challenges about being disbelieved by health and education professionals as their child 'masked' behaviours demonstrated at home, thereby, delaying referral for an autism assessment. Support for parents and carers whilst waiting for assessment and post-diagnostic support was sparse. Parents feel left to manage issues such as: challenging behaviours; anxiety in attending school; and issues around food and sleep in isolation. This in turn affects parental mental health and sometimes their ability to maintain employment leading to further challenges.

High Level Aims

- Reduce waiting times for autism diagnostic assessments.
- All health professionals will have a minimum standard of training and skills in supporting autistic people to access services and pro-actively seek to make reasonable adjustments.
- A range of reasonable adjustment tools are routinely available within health services to enable autistic people to select how they access services and attend/interface with appointments based on their needs.
- Promote understanding of the mental health and well-being needs of autistic people.
- Child and Adult Mental Health professionals have inclusive practice and skills to adapt treatments to meet the individual support needs of autistic patients.
- Improving timely access to mental health services for autistic individuals.
- Improve pre- and post-autism diagnosis support for autistic children, young people and their families/carers which includes: 1:1; groups and peer support on understanding what autism means, developing skills and strategies to support daily lives and advocacy to navigate the system.
- Ensure the Autism Support Service is meeting the post-diagnostic needs of autistic adults.

Key Actions

- Implement the Oliver McGowan Mandatory Training (OMMT) Programme for Learning Disabilities and Autism in all health service settings.
- Roll-out of Reasonable Adjustment Digital Flag from the beginning of April 2024.
- Participate in the national roll-out of Annual Health Checks for autistic people.
- All Health Services (inc. General Practices and Emergency Departments) are signed-up to the Sensory-Friendly Environments in Primary Care Initiative.
- Design a 0-25 years Neurodevelopmental Care Pathway including combined diagnostic assessment process for autism and ADHD.
- Review the current pre- and post-autism diagnostic support offer for children, young people and families/carers.
- Review the Autism Support Service for Herefordshire and Worcestershire to ensure that it is supporting the needs of autistic people to socialise in local communities, participate in activities, access information and advice/support.
- Review processes of assessing the mental ill-health of autistic children, young people and adults within mental health provision (including specialist services).
- Develop an effective system to record autism diagnosis across all health services.

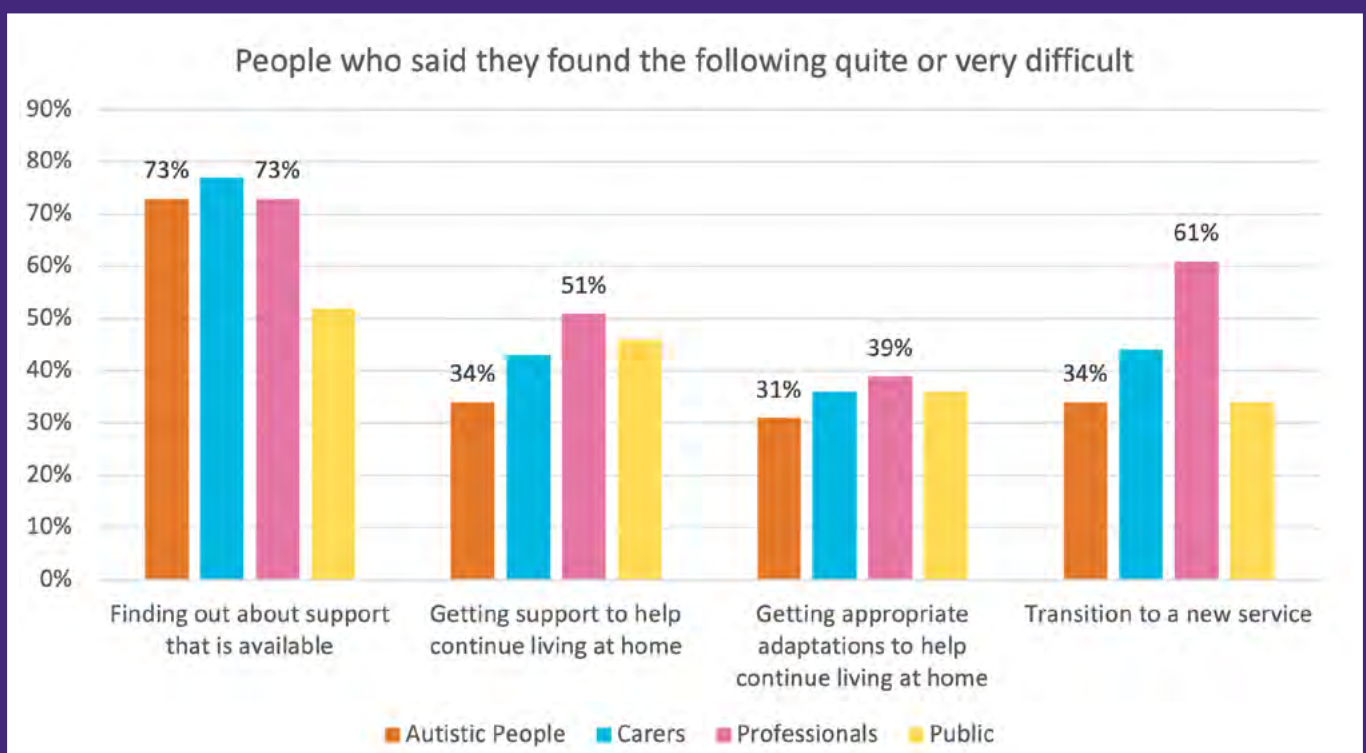


Priority Five: Building the right support in the community.



What do we know?

Autistic people, carers, professionals and the public all identified that finding and getting support in the community was difficult.



Access to information and support in the local community

The consultation identified a wide range of gaps in support for autistic people. There was a particular focus on the need for advocacy support; practical support to navigate systems; and, access mainstream services, with family largely taking on this role and concerns raised as to what will happen when they are no longer able to do this.

Lack of support and fears for the future were often linked with mental health issues and references to suicidal thoughts.

“

A lot of the organisations/ support was in the form of group meetings, which is one of the chief things he finds difficult. He then became increasingly isolated and suffered further mental health problems. What he needed/needs is one-to-one support from an individual he can trust and form an ongoing relationship with.

”

Autism Support Service

There is a new Autism Support Service for Herefordshire and Worcestershire, provided by Autism West Midlands. This is commissioned by Herefordshire and Worcestershire NHS which offers up to 4 1 hour 1:1 Information, Advice and Guidance sessions and a group education programme for diagnosed autistic adults (aged 16+) living in Herefordshire and Worcestershire. Alongside this, they offer well-being walks across both counties as well as peer and social groups open to anyone identifying as autistic. They also have a Helpline service open to autistic people (diagnosed or undiagnosed), parents, carers, family, friends and professionals.



Access to the right assessments and support from social care for autistic people and their carers.

Of those autistic people that felt they needed access to a social care assessment, only 15% of respondents found it very easy or quite easy getting an assessment. Over 70% of respondents said that they were not receiving the help they needed – this was even higher for autistic carers who struggled to get the help needed for themselves.

Through the engagement autistic people of all ages expressed a desire to learn life skills to live independently and a need for community-based support to develop these life skills and support with big life changes.

Herefordshire and Worcestershire have relatively small numbers of people with autism in Long Stay Hospitals. A dynamic risk register of individuals at risk of admission is held and monitored across the ICS, there are currently 75 autistic individuals on the register (flagged as Red and Amber), demonstrating that most of the work is focussed on admission avoidance to prevent people being admitted to a hospital.

There is a lack of specialist community provision in Herefordshire and Worcestershire to discharge individuals back into the community.

Commissioners are working to develop services to meet eligible social care needs and to support hospital discharge in both counties.

Appropriate housing/housing advice

Our strategy engagement found that the majority of autistic people were living at home with family.

73% of people were satisfied with their current housing. However, for those who were not satisfied the effects were far reaching.

Of the people who were dissatisfied with their current housing: loneliness, noise levels and the wrong location were the most common reasons why autistic people were dissatisfied. Whereas carers identified the lack of space as a major reason why current housing was unsatisfactory.

“

Trying to convince the council the autistic child needed their own bedroom as he couldn't share with sibling.

”

Individuals described challenges in accessing social housing and for those in social housing, finding the environment not appropriate for their needs and having adverse effects on their mental health.

“

Where I live is massively unsuitable and causing me severe decline.

”

High Level Aims

- Information about local services to be easily available to autistic people.
- Autistic people should have access to appropriate support in the community and to meet their social care needs if appropriate.
- Carers should have access to appropriate support.
- Appropriate training for people working with autistic people.
- Appropriate reasonable adjustments within housing processes and services to meet the needs of autistic people.
- Appropriate local therapy services to prevent hospital admission/support hospital discharge for autistic people.

Key Actions

- Ensure information about accessible services is available for autistic people.
- Develop a business case for an accessible Hub/s where autistic people can go in their local communities to socialise, participate in activities, get practical support, access information and advice. Specific support services that can meet the needs of autistic people that focus on developing skills and support with big changes.
- Support community inclusion to improve wellbeing and to prevent suicide.
- Raise awareness of Carer Assessments.
- Further analysis of carer feedback to jointly plan support available for families.
- Upskilling people that will come into contact with autistic people. Enable focus on the whole person/whole family approach. Reasonably adjusted assessments and support planning processes.
- Development of an Autism Social Work team in Worcestershire.
- Roll out the Oliver McGowan Mandatory Training (OMMT) Programme across the system.
- Continue to develop Supported Living and residential options for autistic people (including those that aim to avoid admission to hospital or can support hospital discharge).
- Dedicated point of contact to go for housing advice/support.
- Explore use of exemptions (bedrooms) and priority for general needs housing.
- Specialist local mental health and therapy services to avoid admission into hospital where appropriate and support discharge back into the community.



Priority Six - Improving support in criminal and youth justice systems.

What do we know?

Our engagement showed that the most common challenges faced by autistic people in Herefordshire and Worcestershire were:

- Communication difficulties
- Lack of understanding of autism
- Lack of support services
- Negative experiences with the police
- Inappropriate adjustments

Autistic people who were victims of crime were less likely to be told about support services or have their needs met than other victims.

Autistic people who were suspects were more likely to experience negative experiences, such as being arrested for minor offences and being treated unfairly by the police.

“

As a victim of crime, I felt like I was not taken seriously because of my autism. I was not told about my rights or support services.

”

“

The police interview was very stressful, and I felt like I was not being understood. I was not offered any support or adjustments to help me.

”

“

I was arrested for a minor offence and treated unfairly by the police. I felt like I was being discriminated against because of my autism.

”

Respondents also identified two key issues with the way autistic people are treated by the police:

1. Autistic people are often handcuffed and detained in vehicles when experiencing a mental health crisis. This can be isolating and exasperating for autistic people and does not help to reduce the crisis.
2. Police officers need more training and understanding of autism. This would help them to better handle autistic people who are witnesses to crimes or incidents, or who are experiencing a mental health crisis.

Carers also found that autistic people who have had bad experiences with the police in the past are less likely to report crimes or contact the police if they become victims of crime. This is because they do not trust the police to help them or treat them fairly.

It is important to develop a positive relationship between autistic people and the police. This can be done by providing police officers with training on autism awareness and handling methods. It is also important to ensure that autistic people who are victims of crime have access to support services.

High Level Aims

- Everyone working in the criminal justice system should understand the strengths of and challenges facing autistic people.
- Appropriate reasonable adjustments within criminal justice services.
- Autistic people who are victims of crime should have access to support if they want it.
- Reduce the number of autistic people who are involved in the criminal justice system as suspects.

Key Actions

- Training for police officers, lawyers, judges and other professionals involved in the criminal justice system.
- Reasonable adjustment guidance for staff including providing quiet spaces for interviews, allowing autistic people to bring a support person with them, using plain language.
- Work with victim support organisations to develop specialised services for autistic people.
- Work to divert autistic people away from the criminal justice system for minor offences, by providing support to autistic people who are at risk of offending.



Priority Seven – Keeping Safe

What do we Know?

82% of respondents choosing to answer questions relating to 'Keeping Safe' felt more at risk related to autism. The key points are summarised below:

- Lack of understanding of autism and the presentation of autistic traits can mean that communication can be seen as rude or confrontational by neurotypical people.
- These differences in communication can put autistic people into difficult situations and leave them open to hate crimes and bullying. Autistic people also feel they are unable to recognise risky situations thereby leaving them open to exploitation.
- Some respondents noted that the lack of understanding amongst the wider population was often a source of misunderstandings or conflict. Sometimes this led to escalation of situations especially when dealing with official bodies such as the Police and Social Services.
- When asked about issues that worried them people cited using public transport, dealing with money, sexual violence, accessing health services, including mental health support.

People felt that support was needed to help autistic people feel safe through:

- 'Formal Support' (this was not always specified) and doing courses on things such as personal safety.
- Help, advice and guidance through things such as advocacy and being able to access justice where someone feels they are not getting a fair deal.
- Life-coach/peer support approach where support is to plan positively, rather than to wait for failure and give support in crisis.

“

Having a line of support/
someone who 'gets it'
and is kind can help
when things go wrong is
important for us all and
those who care for us.

”

High Level Aims

- Autism needs to be celebrated, promoting the positives and offer support strategies for the things people find difficult.
- We need to facilitate better understanding and awareness of the reasons autistic people may feel unsafe and ways to manage risks and help avoid harms and difficult situations arising in day-to-day life.
- We need to work to reduce incidents of hate crime and improve support provided to autistic people at risk.
- We need to identify resources and support to enable more accessible peer support groups and hubs with local communities to be developed.
- More autism specialist support and expertise around risks and personal safety within public services.

“

Some support should also be aimed at people with lower support needs, since they tend to slip through the cracks compared with people with high support needs. They still need support and sometimes in a more complex way.

”

“

We need to feel understood and not like we are being considered a nuisance and/or dismissed, which unfortunately, is often the case when we ask for a reasonable adjustment.

”

Key Actions

- Develop appropriate training in relation to keeping safe to be available to a wide range of people and organisations.
- Help for people to build a crisis plan, circles of support to build their confidence; resilience strategies; and, have a plan when things don't go to plan.
- Focus on work to reduce isolation and loneliness through support networks, facilitating connections in the community and establishing more opportunities for people to meet and socialise in safe spaces.
- Gather evidence of good practice in other areas and use this to develop ideas for implementation in relation to the key themes outlined within this priority area for example: training, peer and professional support aimed specifically at reducing risk and helping people keep safe.
- Continue with further consultation involving autistic people about what needs to happen within their own area according to different needs, choices and lifestyle.

Who needs to be involved in the change?

This is the list of people/organisations identified as partners in delivering this strategy and action plans. However this Autism Strategy is for everyone and this list is by no means exhaustive. We would like organisations in Herefordshire and Worcestershire to adopt the aims in their own individual strategies to support leading the change.

- Autistic people and their families
- Carers
- Autism Partnership Boards
- Health Commissioners
- Adult Social Care Commissioners
- Health professionals
- Social care professionals
- Worcestershire Children First
- Councillors
- Local communities
- Charitable organisations
- Voluntary organisations
- Retailers
- Museums
- Libraries
- Leisure centres
- Cinemas
- Police
- Fire service
- Local Education Providers
- Employers
- Careers services
- Ambulance Services
- Department of Work and Pensions
- Commissioners
- Schools/Colleges & Universities
- ICS HR Directors
- Health care providers
- Social Care providers
- District Councils
- Housing officers
- Landlords
- Courts
- Victim Support Services



Term	Definition
ADHD	Attention Deficit Hyperactive Disorder (ADHD) is a neurodevelopmental condition that affects people's behaviour. People with ADHD can seem restless, have trouble concentrating and may act impulsively.
Advocacy (informal)	Where a person or organisation supports an individual to make choices/decisions and make their views known. They can support a person to take action to gain access to services or support that they are entitled to.
Autism Friendly Schools Standard	The Autism Education Trust (AET) School Standards are structured around eight key principles that provide the framework for the development of whole-school approaches (ages 5–16) to enhancing provision for autistic pupils and their families. These standards support School leaders to meet special educational needs and disabilities (SEND) policy and legal requirements and their equality duties whilst complying with the Ofsted Education Inspection Framework (2021) and the Teacher Standards (2011). They also align with the Head Teacher Standards (2020).
All-Party Parliamentary Group on Autism (APPGA)	The APPGA is a cross-party group of MPs and Members of the House of Lords who work together to push autism up the agenda in Parliament. The National Autistic Society performs the role of secretary to the group.
Autism	A lifelong developmental condition that affects how people communicate and interact with the world. Often referred to as a spectrum condition because of the range of ways it can impact on people and the different level of support they may need across their lives.
Autism Partnership Board	Set up in each county to inform and shape a local autism strategy and action plan, monitor and review its progress and adherence with the Autism Act 2009. Has a membership made up of autistic people, family carers, professionals from health and social care and providers of services.
Autistic People	People of ALL ages who have a formal diagnosis of autism, self-identify as autistic or may be autistic and do not know.
Carer/s	A carer is anyone, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.
Commissioners	Understand, plan and secure health and/or social care services for the local population.

Term	Definition
Emotionally Based School Avoidance (EBSA)	EBSA can be used to describe the inability of a young person to attend school for long periods of time based on emotional factors. EBSA is not a mental health difficulty but rather a combination of lots of different factors. The combination of factors differs for each individual and there is no single cause although there is often an underlying presence of anxiety and/or emotional distress and no significant anti-social behaviour.
Education Health and Care Plan (EHCP)	An Education Health and Care Plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHCPs identify educational, health and social needs and set out the additional support to meet those needs.
Education Health and Care Assessment/EHC Assessment	A needs assessment carried out by the Local Authority for children and young people who may need an EHCP.
Graduated Response	Special Educational Needs (SEN) support is also known as the Graduated Response.
Health and Wellbeing Boards	The Health and Wellbeing Boards bring together the organisations responsible for improving health and wellbeing and reducing health inequalities for each county.
Integrated Care System (ICS)	An integrated care system (ICS) is when all organisations involved in health and care work together in different, more joined-up ways. The focus is on providing care in a way that benefits patients. In April 2021, NHS England formally accredited Herefordshire and Worcestershire as an Integrated Care System.
Herefordshire and Worcestershire Integrated Care Board (ICB)	The Herefordshire and Worcestershire Integrated Care Board (ICB) is part of the Herefordshire and Worcestershire Integrated Care System (ICS) and is responsible for improving health outcomes for our local population, reducing health inequalities, and supporting broader social and economic development.
H&W ICS Developing Services for Autistic People Programme Board	This Board leads on the development of services for autistic people across Herefordshire & Worcestershire and ensures that the developments proposed in the Learning Disability and Autism 3 Year Plan are delivered.
LeDeR strategy/programme	<u>Learning from the lives and deaths - people with a learning disability and autistic people Herefordshire and Worcestershire Strategy 2022-2025</u> provides a strategic overview of who is involved in the LeDeR programme for Herefordshire and Worcestershire and how they work together. The strategy reflects what has been learnt so far, what it aspires to achieve to improve services and health outcomes for local people and how it plans to do this.

Term	Definition
Looking to the future plan	This is a plan about planning for the future which starts from the earliest point; planning for skill development, choices and opportunities that lead towards a healthy and happy adulthood right from the start. A successful transition into school, making choices, access to the community, different types of transport, communication skills are all examples of planning that helps the child and/or young person as they move towards preparation for adulthood.
Masking (also referred to as camouflaging)	Where an autistic person hides their autistic traits and/or behaviours in certain social situations to better fit in with those around them. Masking can have a significant negative impact on the autistic person's mental health and wellbeing.
National Autism Prevalance Tool	A tool that helps understand the estimated population of autistic people in each county.
Oliver McGowan Mandatory Training (OMMT) Programme	A mandated training programme that has been set within the Health & Social Care Act in 2022, as well as within a new national Code of Conduct. All CQC registered health and care delivery organisations for older people, adult and children's health and social care will be inspected to ensure they follow the code. It aims to ensure the health and social care workforce have the right skills and knowledge to provide safe, compassionate and informed care to autistic people and people with a learning disability (Taken from Health Education England).
Reasonable adjustments	The Autism Act 2009 and the Equality Act 2010 place a duty on public services to take reasonable steps to enable disabled people/person to have access to the same service/s as non-disabled people. This can be through adapting the environment of a building or room, a change to a policy, or working practice or by providing extra support.
Reasonable Adjustment Digital Flag (RADF)	The Reasonable Adjustment Digital Flag is a national NHS initiative which puts a digital 'flag' on patients records so health professionals are aware that a person needs them to tailor support and make adjustments to help them engage with their care. To see an example of the digital 'flag' symbol on a health record click on this link: Reasonable Adjustment Flag case study (based on pilot version of the flag) - NHS Digital
Special Educational Needs (SEN) support	Support that is additional to or different from the support generally given to other children of the same age. The purpose of SEN support is to help children achieve the outcomes or learning objectives set for them by the school (taken from SENDIASS).

