

Wiltshire autism strategy 2022-2027

Executive summary

This joint, all-age autism strategy is guided by a vision of an inclusive, vibrant, well-connected Wiltshire, in which children and young people with autism and autistic adults fulfil their potential, be actively involved and included in their communities, make informed decisions, have control over their lives, and be valued and included within society.

Through consultation and co-production, we have identified six priorities and three enablers. Underneath each of these priorities are actions which will move us closer to realising this vision. Appendix 1 of this strategy shows how these priorities align to the national autism strategy, BSW roadmap and priorities identified by autistic people locally.

Priorities



How we'll make this happen

Create positive and ongoing dialogue between autistic people and services

1.Improve data collection and reporting to monitor implementation of the strategy and drive system improvement

1.Strengthen governance, leadership and accountability

Actions

Improve the health of autistic people and reduce health inequalities

- Review access criteria for services to ensure support is needs-led, not diagnosis-led
- Redesign neurodevelopmental diagnostic pathways for children & young people in adherence with NICE guidance and timescales
- Following the national consultation process and development of code of practice, roll out Oliver McGowan Mandatory Training to all health and social care staff (including commissioned providers)
- Prioritise and evaluate annual health checks and action plans for autistic people
- Review accessibility of mental health provision for autistic adults and children and young people with autism, e.g. by adapting IAPT services
- Learn from local *Learning from Lives and Deaths. People with a Learning Disability and autistic people* (LeDeR) reviews and report back via BSW LDA programme Board

Support children and young people with autism to play, learn and move into adult life

- Instil a safe, inclusive environment through leadership and commitment to inclusion
- Provide children, young people and parents with the right information at the earliest opportunity
- Roll out training for education staff and leaders – e.g. through Autism Education Trust partnership
- Ensure schools and settings are designed, and strategies implemented, around the specific needs and wishes of pupils
- develop a continuity of provision, so that education is flexible enough to adapt to a student's changing needs
- Ensure the perspectives and wishes of autistic young people are at the forefront of the Preparing for Adulthood programme within the SEND strategy, and that planning starts early

Support autistic young people and adults to access work

- Develop a SEND Employment Board in Wiltshire to bring together employers, JobCentres, education providers, local authorities, young people and families
- Raise awareness and provide guidance to employers and JobCentres, e.g. the ACRE profiling tool
- Promote apprenticeships, Supported Internships and Traineeships within the Council and NHS
- encourage organisations and businesses to be autism-inclusive and/or autism-accredited

Support autistic people to live independently in the community wherever possible

- Ensure the perspectives and wishes of autistic people are captured in the implementation and evaluation of the Wiltshire Independent Living Strategy
- All social care staff employed by commissioned providers should access PBS training if they are working with autistic people

- All commissioned social care providers should provide staff with training around de-escalation, communication; and will be contractually required to tell commissioners/regulators about incidents of restraint and seclusion
- Assess the extent to which day opportunities provide more choice and control for autistic people
- Map the crisis pathways
- Develop training for staff to enable them to better meet the needs of people with learning disabilities and autistic people who are experiencing a mental health crisis
- Use NHSE funding to develop key working function

Raise awareness of autism and make Wiltshire an inclusive place to live, learn and work

- Celebrate and recognise the unique skills, attributes, achievements and perspectives of autistic people
- Hear the voice of autistic people around inclusion
- champion guidance to address the sensory impact of buildings and transport
- use campaigns such as National Autism Awareness Week to educate and inform
- share best practice to encourage recognitions and behaviour change from non-autistic people
- Increase the number of people who have autism who are being employed by Wiltshire Council, Integrated Care Systems and other statutory services.

Improve support for autistic people in the criminal justice system

- Work with the Wiltshire Youth Commission to support, challenge and inform the work of the Police and Crime Commissioner for Wiltshire and Swindon and promote greater awareness and understanding of the needs of autistic people
- develop community forensic assessment and treatment services in Wiltshire and Swindon
- Ensure that training is available for staff to give them the skills to support people who are in the criminal justice system
- Raise awareness of PREVENT and ensure that staff have training on this
- Establish robust working relationships between Wiltshire Council, Integrated care systems and the Police

How will we know we have been successful?

- Autistic people will feel included as citizens within their communities
- Autistic people and their families will get clear and timely information, whichever stage of their journey they are at
- Young people will be supported to be ready for an active and meaningful adult life, where they can live, work and build relationships in an inclusive society
- Wiltshire will celebrate and share the skills, experiences and views of autistic people and their families
- There will be a choice of high-quality accommodation and support to enable people to live independently; hospital admissions will be avoided wherever possible, but where hospital is required, discharge planning will start early

- We will narrow the gap in health outcomes, so that autistic people will have the same access to prevention and healthcare

1. Purpose

- 1.1 Wiltshire Council's vision is to create strong communities where people can fulfil their potential, be actively involved and included in their communities, make informed decisions, have control over their lives, and be valued and included within society. In Wiltshire, we start from the strengths, talents and assets that each person has – this means looking beyond their diagnosis or needs, however important these may be. This vision reflects what people in Wiltshire have told us they want to live well.
- 1.2 This strategy highlights how we want to work together to make Wiltshire an inclusive, vibrant, well-connected place for autistic people to live in. It is underpinned by prevention and early intervention, tackling inequalities, understanding our communities, and promoting independence. It responds to national government guidance and legislation and sets out our local priorities.
- 1.3 Reflecting the Bath & North East Somerset, Swindon and Wiltshire (BSW) Partnership (see section 2 below), this is a joint strategy across health, social care and education. We recognise the need to work together to develop a seamless response, as autistic people need support which works in an integrated way to enable them to live a good quality of life. Whilst this strategy addresses priorities in Wiltshire specifically, it fits alongside the BSW Learning Disabilities and Autism (LDA) programme, which is overseen by the BSW LDA Programme Board. The Board will include an over-arching BSW autism strategy in its workplan. The programme is guided by a roadmap whose areas of focus include:
- Improving diagnostic pathways and reducing waiting times
 - Developing better post-diagnosis support
 - Developing autism-friendly environments, including in inpatient settings
 - Developing a workforce strategy and training plan to upskill the workforce
 - Improving uptake of annual health checks
 - Enabling people with the most complex needs to live in the community wherever possible
 - Developing a BSW *Learning from Lives and Deaths. People with a Learning Disability and autistic people (LeDeR)* strategy to prevent people with a learning disability and autistic people from early deaths
- 1.4 It is also an all-age strategy, which means it will seek to meet the needs and wishes of children, young people and adults. Autistic people of all ages should receive the support they need, at the earliest opportunity, to live independently and safely within their community. Wiltshire has started to transform its diagnostic pathways so that children and young people get a timely diagnosis, and this strategy will push that work further.
- 1.5 The purpose of this strategy is:
- **To make Wiltshire an inclusive place** for autistic people to live, learn and work

- To **improve outcomes and opportunities** for autistic people in Wiltshire
- To **help younger autistic people feel ready and confident** about adult life
- To **listen to autistic people and their parents/carers/allies**, and ensure their views and aspirations are at the heart of our priorities and plans
- To **improve the range and quality of services** which help autistic people live independently
- To improve pathways, so people can **access a timely diagnosis and follow-on support**
- To ensure that autistic people and their parents/carers/allies can access **clear, simple information** to help them make informed choices
- To **learn from other areas**
- To **tackle health, housing and care inequalities** for autistic people

1.6 To achieve this, we will all need to work together in a different way. This will require changing our culture and improving our practice. We cannot do this through top-down rules and guidance – we need to work across our communities to ensure that autism is understood, that autistic people’s strengths are valued, and that difference is celebrated. We also need to highlight the individual person – their strengths, talents and aspirations – and not simply their diagnosis.

1.7 This all-age strategy brings together national and local priorities and puts the voice of autistic people and their families, carers, friends and allies at the forefront of our plans. Whilst we are making progress in supporting autistic people and their families, we recognise we have a long way to go to turn the vision of this strategy into reality. We want to support autistic children, young people and adults as they move through the various transitions in life – from early years to school, from primary to secondary school, from adolescence to adulthood etc. That is why this is a five-year strategy, with annual review points to assess how well we are doing.

1.8 The strategy does not stand in isolation but should be seen alongside other key plans, including:

- NHS Long Term Plan
- National strategy for autistic children, young people and adults: 2021-2026
- Wiltshire Whole Life Accommodation & Support Strategy (in development)
- Wiltshire SEND Inclusion Strategy 2020-2023
- Growing Up and Moving On – a guide for young people
- BSW roadmap and forthcoming strategy

2 Local and national context

What is autism?

- 2.1 Autism is a spectrum condition¹ which affects different people in different ways. Autistic people² may experience difficulties with social communication and interaction, repetitive and restrictive behaviour, sensitivity to light, sound, taste or touch, highly focused interests or hobbies, and anxiety and depression.
- 2.2 The definition of autism continues to change as more is learned. Neurodiversity is a movement that challenges perceptions of autism. It rejects the idea that autism is a disorder and sees it instead as a neurological difference: one with a unique way of thinking and experiencing the world. The movement celebrates neurological diversity and champions the different worldviews and skills that people have.
- 2.3 Research shows that public understanding of autism has improved in recent years and that as a society we are becoming more open to neuro-divergence and different ways of being. However, the All-Party Parliamentary Group on Autism's 2019 report found that just 24% of autistic adults and 26% of family members think public understanding has improved since the introduction of the Autism Act in 2009³.
- 2.4 This lack of understanding and acceptance can make it difficult for autistic people to live in a neuro-typical world. Statistics show that autistic people are more vulnerable to anxiety and depression, particularly in late adolescence and early adult life. Autism can also limit an individual's ability to work or find employment – often because society does not understand the experience of the autistic person. 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 disabled people, 81% of non-disabled people⁴ and 5.1% of adults with a learning disability. The same report also found that 31% of employers surveyed said autistic employees would require too much support, and many reported needing more advice on how to support people.
- 2.5 There is some evidence to show a link between gender dysphoria (when a person's assigned sex is different from the gender they identify with) and autism. The reasons for this are not clear, and more research is needed on this subject, as well as how best to support autistic people with gender dysphoria. Anecdotally, we know that there are some young autistic people in Wiltshire who feel unease or distress because of a mismatch between their biological sex and their gender identity.

¹ This strategy generally uses the term autism spectrum *conditions* (ASC) in preference to autism spectrum *disorders*, as research shows this is generally how autistic people prefer the condition to be described. However, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) describes it as autism spectrum disorder, so this term is used when referring to the diagnosis.

² This strategy uses the term "autistic people" over "people with autism," as research by the National Autistic Society nationally and by Wiltshire Parent Carer Council locally found this was generally the preferred description.

³ <https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf>

⁴

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfor-disabled-people-in-the-uk/2020#employment>

Local profile

- 2.6 Bath & North East Somerset, Swindon and Wiltshire (BSW) Partnership is an integrated care system (ICS) made up of NHS, local authority and voluntary sector organisations working together. Its objective is to improve the health and wellbeing of local people, tackle inequalities and achieve better outcomes and access for everyone, ensure that health and care services are high-quality and to make the most efficient use of finite resources.
- 2.7 Within the Partnership, Wiltshire integrated care alliance (ICA) has focused on supporting people to go home from hospital more easily, helping people with long term conditions get the care they need, and providing support for our ageing population and those with complex needs. Wiltshire ICA is moving away from a sole focus on service improvement and integration to improving the health and wellbeing of our population and working collaboratively with the interests of the Wiltshire population at the heart of all decisions. This autism strategy reflects these priorities.

Special educational needs and disabilities (SEND)

- 2.8 Autistic children, young people and their families in Wiltshire have shared their experiences and their vision and priorities for the future. Wiltshire has done well in working towards the goals within the Children & Families Act 2014 and in 2018 we received a positive SEND local area inspection. This was an inspection of how we all work together, including education settings, the Council, WPC, the voluntary sector and health⁵. Alongside a number of strengths, inspectors did identify some areas for improvement around children and young people with autism:

Identifying needs:

- Parents and carers sometimes reported that when they raise concerns, they felt the local area does not always listen
- Autism-related needs of children and young people were not always identified quickly enough
- Lack of specialist placements may sometimes result in breakdown in school placement

Meeting needs:

- There were gaps in autism spectrum condition provision, especially across education and health services
- There was a lack of NICE-compliant autistic spectrum condition pathway
- Some children had to travel significant distances to the appropriate specialist setting
- Parents told inspectors of their anxiety while waiting for a formal diagnosis

Improving outcomes:

⁵ <https://files.ofsted.gov.uk/v1/file/2763765>

- There was a lack of specialist autism education provision in the local area. Strategic plans are currently being finalised to provide resource bases and specialist provision for ASD pupils in the south of the county

2.9 There has been significant work carried out since 2019 to improve support for children and young people with autism and their families, and this is described in Wiltshire’s self-evaluation framework (SEF). This includes developing and enhancing NICE-compliant diagnostic pathways, seeking to reduce waiting times, commissioning post-diagnostic support, and significant engagement and co-production with parents.

2.10 Children, young people and their families tell us they want to remain living with their families, avoiding where possible the need for residential care both now and as they move into adulthood. Children and young people (especially those with special educational needs and disabilities) also tell us that they want to live independently, take risks and try new things – but sometimes feel held back by the worries and anxieties of their parents, or because they cannot access the right support.

Wiltshire System of Excellence

2.11 In response, Wiltshire is establishing itself as a System of Excellence for SEND. The vision for the System of Excellence is for Wiltshire to be a place where we are working together to empower children, young people and families to thrive in inclusive communities. The programme brings together seven key strands of work⁶:

- Better outcomes for children and young people, supporting moves towards independence
- A vision for the whole-age pathway from 0-25 with good transitions, including health and social care input
- Early help which is not driven by an EHCP or diagnosis
- Easier pathways for families, with simpler processes and better information
- Upskilled, confident mainstream settings and schools equipped with resources to support CYP effectively, leading to parent/carer confidence
- An equitable and consistent offer across Wiltshire
- Partnership working across Wiltshire, including with parents and carers

2.12 Adults in Wiltshire say they want to live safely and independently in their own homes for as long as they can and enjoy the best possible quality of life. Our approach is based on people’s strengths and focuses on what people can contribute. This includes supporting people to be ambitious and discover their potential.

2.13 Our vision is therefore for autistic people in Wiltshire to be able to live fulfilling and rewarding lives within a society that accepts and understands them. This means people can get a diagnosis and access support if they need it; can depend on mainstream public services to treat them fairly as individuals and

⁶ See Appendix 1 for 9 “I statements” which have been drafted during the development of this work

help them make the most of their talents in an accessible physical environment; and can expect to play an equal part in the local community, get the right support at the right time throughout their lives and develop their skills and independence and work to the best of their abilities.

National strategy

2.14 This echoes the vision and objectives of the National Autism Strategy, published in 2021, which prioritises:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

2.15 This plan is also informed by the NICE⁷ autism quality standard (QS51), and clinical guidelines: Guidance on Autism in under 19s (CG128 and CG170) and Autism in Adults (CG142). The national Learning disabilities and autism (LDA) programme aims to make health and care services better so that more people with a learning disability, autism or both can live in the community, with the right support, and close to home. The 2015 report *Building the right support*⁸ sets out how we will ensure that people get the right care, in the right place at the right time. Wiltshire is part of the Bath & North East Somerset, Swindon and Wiltshire (BSW) LDA programme, which has published a roadmap to improve outcomes for people with a learning disability, autism or both. Progress on delivering the roadmap is subject to rigorous reporting to and scrutiny by NHS England.

3 Co-production

3.1 Autistic children, young people and adults, as well as parents and carers, have given feedback on the current offer through a range of forums, both online and in-person. This section provides a snapshot of that feedback and includes direct quotes from people who contributed.

3.2 In November 2021, Wiltshire Service Users' Network (WSUN) and Healthwatch Wiltshire published the results of a survey of over 100 autistic adults and/or adult carers of autistic adults, children and young people. The report, *What people with autism spectrum conditions think of services*⁹, made a number of recommendations:

⁷ National Institute for Health and Care Excellence

⁸ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

⁹ <https://www.healthwatchwiltshire.co.uk/report/2021-11-15/what-people-autism-spectrum-conditions-think-services>

- Introduce initiatives and training to improve awareness of autism among staff working in GP practices and hospitals.
- Consider offering people with autism a written summary of their appointment, treatment and follow-up.
- Establish a system of recording preferences and/or needs for face to face, phone or video appointments and consider how these preferences can be met as far as possible.
- Establish a system that flags a person’s autism spectrum condition in their medical notes.
- Include the findings of this report in pathway reviews for support services in Wiltshire, with the aim of providing improved access to services for people with an autism spectrum condition.
- Consider how information about, and experience of, transition from child to adult services can be improved.
- Investigate a reduction in the volume of general information given at diagnosis and the provision of a more individually tailored pack.
- Work with people with autism spectrum conditions and their carers in taking forward the above recommendations.

“Long waiting time on the phone makes me anxious, the music or/beeping is overwhelming. [Staff] don’t have awareness that I am autistic.”

“I don’t always understand the language they use, or what information they want.”

“Believe us! If he says he’s in pain but doesn’t react to pain in a neurotypical way, just believe him.”

3.3 In December 2020, Wiltshire CIL asked autistic adults to identify what they felt should be the priorities for the Autism Partnership Board in the coming year. They recommended the following:

Raising awareness about autism	Improving support around practical and emotional life skills	Supporting autistic people into employment
Improving range of independent living options	Creating more social opportunities for autistic people	Creating channels of engagement that work for autistic people

3.4 Autistic people and their families and carers have told us they need a trained and skilled workforce, services that offer continuity and consistency of care and an efficient and accessible diagnostic service. They consistently highlight needs around housing, employment, meaningful day time opportunities, the aging carer population and more recently, the disconnection between children's and adults' services.

3.5 We also know that the COVID-19 pandemic has had and continues to have an impact on autistic people. The National Autistic Society's *Left Stranded* report shows that in June/July 2020 compared to the general public, autistic people were:

- Seven times more likely to be chronically lonely
- Six times more likely to have low life satisfaction

Nine out of ten autistic people worried about their health during lockdown; one in five family members had to reduce work due to caring responsibilities; and seven in ten parents said their child had difficulty understanding or completing schoolwork and around half said their child's academic progress suffered¹⁰. We have heard anecdotally that, perhaps due to the increased pressure caused by the pandemic, increasing numbers of autistic young people and adults are smoking cannabis and drinking alcohol; there is also some evidence of increasing incidence of domestic violence, with autistic people as both perpetrators and victims.

3.6 Autistic people have also clearly stated that the Autism Partnership Board is not working and does not enable people with lived experience to express their views and be heard. We are exploring new and better ways to ensure the voice of autistic people is truly at the centre of what we do, and that we heard the diverse voices of autistic people – from younger and older people, those whose lives are settled and those people living through a period of crisis, people diagnosed and not diagnosed, etc.

4 Our population

4.1 Recent UK research suggest that the diagnosis of autism in children is around 1.76%¹¹ - an increase from 1.57% in a previous study carried out by the same research team using similar methods. This study suggested that there are variations in autism prevalence across different ethnic groups, with prevalence highest in pupils of black ethnicity (2.1%) and lowest in Roma/Irish Travellers (0.85%). Pupils with a record of autism in schools were 60% more likely to also be socially disadvantaged, and 36% less likely to speak English.

4.2 In the UK, around 1.1% of adults is estimated to be autistic. The male-to-female ratio is between 5:1 and 3:1, although it is widely believed that this

¹⁰ <https://www.autism.org.uk/what-we-do/news/coronavirus-report>

¹¹ <https://www.ncl.ac.uk/press/articles/archive/2021/03/autismratesincrease/>

under-represents the number and proportion of autistic girls and women. There is some evidence to show a link between gender dysphoria and autism, although more research is needed on this subject¹². Autism is under-diagnosed in adults of working age (and in older adults in particular), which may be due to autism not having been widely recognised or diagnosable when people who are currently adults were children. Many of these adults are living without support or information, but anecdotally we hear of people who find it challenging when support systems fall away (e.g. when a young person leaves school or college).

A study by the London School of Economics and Political Science¹³ in 2014 estimated that autism is the most costly medical condition in the UK, costing the country at least £32 billion per year in treatment, lost earnings, care and support for children and adults with autism.

4.3 Applied to Wiltshire’s population¹⁴, this indicates that around 5,600 people were potentially living with autism spectrum conditions in Wiltshire in mid-2020, and approximately 1,200 of those will be children or young people. The table below shows how the overall population and the number of autistic people is likely to change in the next 15 years:

	ONS resident population estimated figures				Estimated population of autistic people calculated at 1.1% of resident population			
	2020	2025	2030	2035	2020	2025	2030	2035
Total population	510,050	522,237	531,492	539,257	5,610	5,740	5,850	5,930
CYP	108,896	109,346	106,110	103,757	1,200	1,200	1,170	1,140
Adults	401,154	412,892	425,382	435,500	4,410	4,540	4,680	4,790
Male	252,982	258,496	262,620	265,946	2,780	2,840	2,890	2,930
Female	257,068	263,741	268,872	273,311	2,830	2,900	2,960	3,010

4.4 The next table shows in more detail how many male and female autistic people there are likely to be in Wiltshire across different age groups:

¹² <https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/>

¹³ Buescher A. V., Cidav Z., Knapp M., Mandell D. S. (2014), “Costs of autism spectrum disorders in the United Kingdom and United States of America”. In *Journal of the American Medical Association Pediatrics* | (JAMA) 168(8) pp721-728. Available at: <http://archpedi.jamanetwork.com/article.aspx?articleid=1879723>.

¹⁴ <https://www.skillsforcare.org.uk/Documents/Learning-and-development/Ongoing-learning-and-development/Autism/Commissioner-framework-main-FINAL-150621.pdf>

Estimated population of autistic people calculated at 1.1% of resident population				
	2020	2025	2030	2035
Males				
aged 0 - 4	160	150	150	150
aged 5-11	250	240	230	230
aged 12-15	140	150	140	140
aged 16-17	70	70	70	70
aged 18-24	210	210	230	230
aged 25-34	330	320	310	320
aged 35-64	1070	1060	1030	990
aged 65-79	420	470	500	550
aged 80+	140	170	220	250
Females				
aged 0 - 4	150	150	150	140
aged 5-11	240	230	220	220
aged 12-15	140	150	140	130
aged 16-17	60	70	70	70
aged 18-24	160	150	170	170
aged 25-34	300	280	260	270
aged 35-64	1130	1140	1120	1090
aged 65-79	460	500	540	600
aged 80+	200	230	290	330

- 4.5 It is estimated that 40% of autistic people (i.e. around 2,500 people in Wiltshire) will also have an anxiety disorder, and one third (around 2,100 in Wiltshire) will also have a learning disability.
- 4.6 Health professionals will usually not give a diagnosis of autism spectrum condition to a child under two years old, and the average age of a childhood autism diagnosis in the UK is around four-and-a-half years old. Waiting times and numbers of young people waiting for assessment of autism spectrum condition (ASC) are a national problem, and in Wiltshire demand is increasing and waits are often excessive.
- 4.7 In Wiltshire, there are around 8,500 children and young people with SEN Support needs and a further 4,300 with an Education, Health and Care Plan. Wiltshire's SEND Inclusion Strategy identified that communication and interaction was the most common SEND designation for children in primary school. In line with national trends, there has been an increase in the number of children and young people with autism as their primary need; in 2021, there were around 1,100 CYP in Wiltshire with a primary need of autism, split as follows by Key Stage:

Key Stage	Numbers with EHCP / ASC as primary need
0 (aged 3-4)	114
1 (aged 5-6)	136
2 (aged 7-10)	368
3 (aged 11-13)	259
4 (aged 14-15)	163
5 (aged 16-17)	120

4.8 In 2021, Wiltshire Council supported approximately 500 adults with a diagnosed autism spectrum condition, most of whom also have a learning disability and/or mental health needs. The number of autistic social care customers has increased significantly in the last five years. The Wiltshire Independent Living Strategy 2022/27 commits to improving the quality and choice of housing, care and support to these people; in particular, we know that the needs of autistic people who don't have a learning disability are often not well met.

4.9 A needs analysis carried out in 2018 showed that nearly two thirds of commissioned social care and housing providers reported limited ability to support autistic customers and that autistic customers often don't have a smooth transition between children's and adults' services.

Wiltshire CCG Autism Spectrum Disorder Workshop – March 2020

4.10 In December 2019, the BSW LDA Programme Board agreed to map out services and pathways in each locality, focusing on what works well, as well as gaps and issues. The scope included the whole life pathway, i.e. both children and adults, as well as transition. Themes emerging from these discussions included:

- people having nowhere to go following diagnosis,
- maze-like pathways of accessing an assessment and diagnosis,
- many cinemas, theatres and shops have improved the environment for autistic people, and we can learn from them,
- the adoption of yellow cards / sunflowers to indicate safer places,
- the need for better support for autistic people,
- issues with people getting a diagnosis privately and then not being able to access public services,
- the need to share stories to share information and good practice.

4.11 When asked to think of suggestions as to how the experience of autistic people could be improved, the most popular suggestions were:

- Improvement in transitions from children's to adults' services,
- Better understanding of autism within "generic" services,
- Sensory needs,
- Pre-assessment of support around expectations and how to manage them,
- Support for behaviour that may challenge some people.

5. Our priorities

The six areas we will prioritise in this strategy are drawn first and foremost from what autistic people in Wiltshire have said is important to them. These priorities also align with the roadmap across BSW and the national autism strategy, which was published in 2021. This section describes those priorities and the things we will do to achieve the vision set out at the beginning of the strategy.

Across BSW, we have had to revise our NHS-funded investment proposals in 2021/22 to align with available funding from NHS England. In 2021/22, the following investment is being made to improve health outcomes for people with learning disabilities and/or autism spectrum conditions:

- £194,000 to transform the diagnostic pathway for children and young people
- £84,000 to level up the Swindon adult autism diagnosis services
- £70,000 into infrastructure and enablers for the delivery of the BSW LDA strategy
- £47,250 to develop community forensic assessment and treatment services
- £45,000 to create autism-friendly health and social care environments

5.1 Improve the health of autistic people and reduce health inequalities

5.1.1 NICE guidance states that nobody should wait more than 13 weeks between referrals and initial assessment. Diagnostic services are seeing increasing demand for assessments, and this is believed to be for various reasons: better public awareness of autism, a build-up of people on the waiting list during the pandemic, pathways which do not differentiate between different levels of need and different types of presentation.

5.1.2 There is also an understanding amongst some parents that a diagnosis of autism spectrum disorder (like an Education, Health and Care Plan) will enable them to access support. This creates a perverse incentive for parents to get a diagnosis and we need to move away from support which is *diagnosis-led* to that which is *needs-led*.

5.1.3 One of the central planks of the BSW LDA roadmap is to transform diagnostic pathways for children and young people. Waiting times and lists for children and young people vary across BSW; this is a national problem, and in Wiltshire at the beginning of 2021/22 there were nearly 1,700 children and young people waiting for a diagnosis. However, in Wiltshire all parents will have contact with the diagnostic team early in the process. This initial contact will consist of a robust triage, initial interview, and formulation to determine the appropriate diagnostic pathway, depending on complexity.

5.1.4 The autism Waiting List Initiative (WLI) is a collaboration across autism assessment services in BSW. The aims of the initiative were to provide additional assessment capacity to reduce the numbers of CYP waiting, to

enhance joined-up working, increase efficiency by ensuring each child or young person is on the most appropriate pathway for their needs, and to increase accessibility for children, young people and parents. This has involved creating a differentiated assessment pathway to increase efficiency (meaning that young people undergo the minimum required assessment elements for a comprehensive autism assessment); using digital methods of assessment initiated during the pandemic to increase efficiency in service delivery; and creating a truly multi-disciplinary team of professionals with different expertise and experience of local service.

5.1.5 During Wave 1 of the WLI, families of children and young people who had been waiting for longest were invited to opt into the new initiative. Of those who accepted the invitation in Wiltshire, the gender ratio was around 60% male / 40% female, the average age at referral was approximately eight-and-a-half years old (with a range between three-and-a-half and 14-and-a-half), and about two thirds received a diagnosis of autism spectrum conditions (with the remaining third either being signposted to alternative diagnostic pathways or having an inconclusive diagnosis).

5.1.6 These new ways of working have been evaluated to develop a sustainable neurodevelopmental assessment pathway which is consistent with NICE guidance. A single point of access for referrals is being scoped and will be launched in the next 18 months. This neurodevelopmental transformation programme also includes the development of an ADHD pathway, improving support for parents both pre- and post-diagnosis, and working with referrers (particularly schools and GPs) to improve the quality of referrals. The objective is to roll out best practice and ensure an equitable offer across BSW. There is also a programme of work across BSW to address waiting times for adults on the diagnostic pathway.

5.1.7 Leaders in education settings also report that education staff need better support to be able to identify possible indicators of autism early, so the child can get a timely assessment, diagnosis and post-diagnostic support. The further development and refinement of NICE-compliant assessment pathways should be done in conjunction with early years and school providers – e.g. through joint working between paediatricians and District Specialist Services.

5.1.8 Research collated by Autistica¹⁵ also shows that autistic people experience poor health outcomes in other areas, e.g.:

- Approximately 1 in 5 women with anorexia in eating disorder services are autistic. However, research is beginning to explore how **anorexia and other eating disorders** may differ autistic and non-autistic people.
- It is believed that up to 11% of people who die by **suicide** each year are autistic, compared to 1% of the general population. Factors known to increase risk of suicide (e.g. social isolation, unemployment, trauma, abuse and other social and biological factors) are more common amongst autistic

¹⁵ <https://www.autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf>

people. However, many autistic people say they struggle to access appropriate support for mental health problems or suicidal thoughts.

- **7 in 10 autistic children have a mental health condition.** 4 in 10 autistic children have more than one. There is a developing body of evidence around the need to adapt therapies such as cognitive behaviour therapy and the increased effectiveness of these therapies when adaptations are made.
- **Almost 8 in 10 autistic adults experience a mental health problem** and up to 10% of adults in inpatient mental health settings are autistic. National research by Autistica suggests that the number one research priority for autistic people, families and researchers is finding and adapting interventions to improve mental health.
- Autistic people face substantial **health inequalities** and the available evidence indicates that autistic people die on average 16 years earlier than the general population (there is a health inequalities sub-group of the LDA Programme which is tasked with tackling these challenges).
- Some autistic people are less likely to interpret signs of ill-health and many face **barriers to accessing NHS services**. Health checks can help proactively focus support towards groups facing health inequalities.
- **Between 15% and 40% of people with epilepsies are autistic**, compared to just 1% of the general population. Epilepsies are particularly prevalent amongst autistic people with a learning disability.
- **Many autistic people are prescribed psychotropic medication**, such as antipsychotics, for long periods, even if they haven't been diagnosed with the conditions those drugs are intended to treat. The long-term use of psychotropics is associated with a range of health problems.
- Between two thirds and three quarters of **adults wait longer than the recommended 12 weeks in NICE guidelines for an assessment**, with one third waiting longer than 18 months. Nationally and locally, Services are often not commissioned or funded to support people after diagnosis.
- **Women and girls** tend to be diagnosed later and are less likely to receive a diagnosis than men and boys with similar levels of autistic traits.

5.1.9 We need to improve the quality of community support – including housing, social care and mental healthcare – so that autistic people are supported earlier and prevented from reaching a crisis. For the small number of autistic people who do need inpatient care, that care should be high quality, therapeutic and tailored to their needs, and as close to home as possible.

5.1.10 We will take action to improve the accessibility of mental health services for autistic people, via the BSW Community Mental Health Service Framework. We have funding in 2022/23 to audit psychiatric inpatient settings, to ensure they are autism-friendly. We will use this funding to train experts by experience to undertake onsite audits, report back to the provider of the ward, and recommend adjustments to make the physical and sensory environment more conducive to recovery. We will also share this learning with other organisations, e.g. providers of supported living, GP practices etc.

5.1.11 We will also work with our children, adolescent and adult mental health service providers to make sure that autistic people can access support which is

tailored to their needs. We will promote access to talking therapies and evaluate how accessible these services are for autistic people.

5.1.12 The inequalities and poorer health outcomes experienced by autistic people will be reduced by raising professional awareness of autism. For example, research shows that some of the barriers faced by autistic people are because differences in identifying one's own emotions and responding to pain are not always understood and recognised by professionals, which can lead to mutual miscommunication. The Oliver McGowan Mandatory Training is undergoing national evaluation, and once this is complete it will be rolled out to all NHS and care staff to help them learn and share the best ways of working with people with a learning disability and/or autism. In Wiltshire we want all social care staff (including those employed by voluntary or private sector organisations working in the County) to benefit from this training too.

5.1.13 Annual health checks are also critical to identifying and meeting autistic people's health needs. Wiltshire has prioritised annual health checks for people with learning disabilities and autistic people. Clinics are offered in GP practices and community settings, and health practitioners are working with special schools to promote annual health checks for young people aged 14-25. Performance is monitored by the BSW LDA Programme Board, and provision will be evaluated by the University of Bristol.

5.1.14 For the first time in 2021, NHSE/I's Learning from Lives and Deaths – People with a Learning Disability and Autistic People programme (LeDeR) includes autistic people. This means that any person aged 4+ with a diagnosis of a learning disability or autism spectrum disorder is eligible for a LeDeR review. In 2021, the BSW Partnership also published its three-year LeDeR strategy which will raise professional awareness of how to report a death, sets out a process for system learning and action, and provides clear governance and quality assurance.

5.1.15 Autistic people should also be given support to move from one health service to another – e.g. transferring from Child and Adolescent Mental Health Services (CAMHS) to adult mental health services. Services should work with the young person to prepare them for such a move, introduce them (or support the person to introduce themselves) to their new worker, and ensure they know how to get support. All professionals should work with the young person, parents and others in the person's network to ensure they have a plan after they leave school

5.2 Support children and young people with autism to play, learn and move into adult life

5.2.1 There are approximately 7,000 children in **early years** settings in Wiltshire¹⁶. There are 12 children's centres in Wiltshire, offering a range of play, activities and support (including sensory spaces); pathways into midwifery, health visitors, the Special Educational Needs and Disabilities (SEND) service and

¹⁶ Wiltshire SEND Inclusion Strategy 2020-23

ASC diagnostic pathway. Parents can also access parenting programmes and advice about local childcare, up to 15 hours of term-time childcare for some two-year-olds with an EHCP and all three- and four-years-olds.

5.2.2 There are approximately 70,000 children and young people in Wiltshire's **schools**. Around half of CYP with an education, health and care plan (EHCP) are in a mainstream school, resource base or enhanced learning provision. Nationally, we know that 1.5% of school-aged children and young people are autistic but account for 2.5% of exclusions. In Wiltshire, whilst the rate of autistic students with fixed term exclusions is reducing, the overall number is increasing (this is mainly because the overall number of students with a diagnosis of autism is increasing). Three quarters of autistic students with an education, health and care plan (EHCP) or SEN support go to a mainstream school, and national research indicates that many autistic students don't feel supported but feel that having a teacher who understands autism is the most important thing in terms of their experience of school.

5.2.3 Early years leaders report more openness and acceptance in talking to parents about autism. Wiltshire's SWAPP courses are invaluable for providing parents with information and reflective support, which is tailored depending on the child or young person's age. A member of staff from the child or young person's setting/school is encouraged to attend whenever possible in order to develop a consistent approach around the child or young person.

5.2.4 However, whilst we have made significant progress as a system, further improvements are needed in the support that children and parents get, especially if they are waiting for a diagnosis. Parents should be able to access both professional and peer support, and some children in early years settings would benefit from specialist behavioural support.

5.2.5 We will continue to roll out awareness-raising and good practice training and will look at ways to expand this so that all education staff and leaders can benefit. Our aim is to improve staff confidence; make mainstream education inclusive; enable self-advocacy; improve attendance & engagement, reduce exclusions – and we will measure our effectiveness against these.

5.2.6 We want children and young people to be in the setting that best meets their needs, and for many with autism this will be a mainstream school. Inclusive schools can lead the way in celebrating difference and diversity and encouraging a more inclusive society. The SEND System of Excellence will aim to create a positive culture which all of Wiltshire's settings and schools sign up to and feel confident practising. This culture change means removing barriers to inclusion – for example, thresholds that require an autism diagnosis before a young person can access support. Physical space, both outside and indoors, needs to be designed in a way that takes account of students' differing sensory needs.

5.2.7 We need to develop a continuity of provision, so that education is flexible enough to adapt to a student's changing needs, rather than expecting children and young people to fit into boxes. There also needs to be flexibility in the

system to allow students to move out of specialist provision into mainstream if that is right for them. This flexibility already exists in early years settings, where children can have a dual placement between District Specialist Centre and mainstream, with flexible outreach and in-reach.

5.2.8 Whilst there needs to be sufficient supply of special school places to meet needs, we also need to recognise that until we have mainstream education provision that is genuinely inclusive, our need for special school places will inevitably increase. Inclusive mainstream provision is crucial in ensuring we use our specialist education provision most effectively. To this end, we aim to become an Autism Education Trust partner.

5.2.9 Wiltshire has recently launched its Growing up and moving on guide, which provides young people and their families with information around education, employment and training, independent living, being part of their local community, and health.

5.2.10 As well as transitions from education into adulthood, there is also a need to ensure that changing year groups and moving schools is personalised around the pupil. Pupils should have the opportunity to visit their new school or class room, meet their new teacher, and teachers should be aware of any individual needs and strategies in advance. Usually, a good transition hinges on good preparation and strong communication between settings. Early years and school settings should meet regularly to review recent transitions, identify strengths and areas for improvement, and apply these lessons.

5.3 Support autistic young people and adults to access work

5.3.1 National research shows that unemployment rates are exceptionally high amongst autistic people, even compared to other disability groups. Autistic people also face high rates of underemployment. For those who do find work, it is disproportionately part-time, temporary, casual, or roles for which they are overqualified¹⁷. This may be partly due to ways of recruitment – e.g. interview processes, tests of social ability, abstract questions – which inadvertently discriminate against autistic people. The result is that autistic people are often excluded from the workplace, and employers miss out on the skills and experience that autistic people can bring.

5.3.2 The national autism strategy recommends that each local area develops a Supported Employment Forum which brings together employers, JobCentres, education providers, local authorities, young people and families to help young people to develop the skills which will enable them to find work. Education and training must be aligned to employment gaps in Wiltshire.

5.3.3 Supported Employment Forums can also promote awareness-raising amongst employers and JobCentres and provide guidance to help create autism-friendly

¹⁷ <https://www.autistica.org.uk/downloads/files/Building-Happier-Healthier-Longer-Lives-The-Autistica-Action-Briefings-2019.pdf>

environments. The Autism Centre for Research on Employment (ACRE) is funded by the University of Portsmouth to provide free profiling assessments to help autistic people to find work. These tools also help JobCentres to signpost and provide support to autistic people who don't have a learning disability. These tools should be promoted and used across Wiltshire.

5.3.4 The national strategy also aims to increase the number of autistic people who can access and succeed in apprenticeships, as well as Supported Internships and Traineeships.

5.4 Support autistic people to live independently in the community wherever possible

5.4.1 Wiltshire has a range of community assets. These assets should be accessible and inclusive to everyone who lives, works or learns in the County. Every autistic person has a range of strengths, aspirations and abilities. We want to support these strengths and help autistic people realise their aspirations.

5.4.2 All services and activities in Wiltshire should be as inclusive as possible for autistic people. We want to see children and young people with autism flourishing in mainstream education, with good quality specialist provision for those with the most complex needs. We want pathways to provide young autistic people with opportunities beyond education, which enable people to transition smoothly into an adult life of independence. We want to support and challenge universal services (both public and private sector) to be autism-friendly, so that autistic people have the same opportunities as their peers.

5.4.3 Nationally, the number of autistic people being discharged from inpatient psychiatric settings is increasing; however, too many autistic young people and adults are being admitted to these settings because the right support is not available at the right time in the community. Wiltshire's Independent Living Strategy aims to:

- **Change the way we commission accommodation and support** through an increased focus on performance and outcomes, working with regional partners to develop a market of high-quality, specialist provision, and facilitating stronger partnerships between housing and social care providers. We will generally move away from commissioning residential care, towards supported living and other support which promotes independence.
- **Implement recovery pathways for people with mental health conditions**, including developing a "pipeline" of new supported living projects and improving crisis interventions.
- **Create more housing choices for people** which are designed around the physical, mental, cognitive and sensory needs of the individual.
- **Ensure our pathways and processes are clear** and that we improve our collection and use of data. The strategy also makes a commitment that all new packages of care will be reviewed after 12 weeks, with an expectation that many packages can be reduced as people's needs change.

- **Provide the public with clear information** about what is available, so that people can find the best housing, support and advice which meets their needs and aspirations.

5.4.4 We will also apply the recommendations within the Care Quality Commission’s 2020 report *Out of sight – who cares?* which found that too often difference (for example, neuro-divergence) is dealt with through restraint, seclusion and segregation – this is especially the case in hospital settings, but sometimes in the community too. The report recommends timely diagnosis, earlier intervention, better training (e.g. around de-escalation, communication tools such as PECS and Makaton), review of psychotropic medication (which should only be used as a last resort), and a culture of openness whereby providers routinely tell commissioners/regulators about incidents of restraint and seclusion. As above, experts by experience will undertake onsite audits of ward settings, report back and recommend adjustments to make the physical and sensory environment more conducive to recovery.

5.4.5 In 2022, Wiltshire Council is also taking a new commissioning and procurement approach to transform how disabled young people, adults and older people (including autistic people) access daytime and evenings activities which meet their needs and aspirations in life. This includes a greater focus on goals and outcomes, the development of a service specification that is informed by the views of disabled and older people and the people who support them, and the procurement of an open framework arrangement.

5.4.6 These changes are likely to happen alongside changes to the Mental Health Act (1983) which will affect autistic people. The Government published its White Paper in 2021¹⁸ which proposed, amongst other reforms, that autistic people should only be detained under the Act if there is a likely mental health need. This was in response to a review of the Mental Health Act which found that too many people with a learning disability and autistic people are admitted inappropriately to mental health wards and once admitted, stay in hospital too long. The White Paper also proposes putting any recommendations which arise from Care, Education and Treatment Reviews (CETRs) or Care & Treatment Reviews on a statutory footing.

5.4.7 Crisis pathways and services are also being mapped to determine what additional training needs there are for staff in both community and inpatient settings to enable them to better meet the needs of people with learning disabilities and autistic people who are experiencing a mental health crisis.

5.5 Raise awareness of autism and make Wiltshire an inclusive place to live, learn and work

5.5.1 Whilst public understanding of autism has improved in recent years, we know from listening to autistic people and their carers and allies that we still have

¹⁸ <https://www.gov.uk/government/consultations/reforming-the-mental-health-act/reforming-the-mental-health-act>

some way to go before autistic people feel as included and accepted as non-autistic people.

5.5.2 Specifically, we need to encourage organisations and businesses to be autism-inclusive and/or autism-accredited. This means championing guidance to address the sensory impact of buildings and transport; using campaigns such as National Autism Awareness Week to educate and inform; and sharing best practice to encourage recognitions and behaviour change from non-autistic people.

5.6 Improve support for autistic people in the criminal justice system

5.6.1 The national autism strategy notes that autistic people are likely to be over-represented in criminal justice services, whether as victims, witnesses or defendants. However, their experiences are likely to be poor, due to poor understanding of autism amongst professionals and a lack of reasonable adjustments made. Prisons, police stations, Courts and other criminal justice services are often noisy, brightly lit and are likely to cause sensory distress to an autistic person.

5.6.2 Work is happening nationally with prison and probation staff, developing more autism-friendly environments and improving access to reasonable adjustments. NHSE/I are rolling out a new service called RECONNECT over the next 3 years, to provide care after custody for people leaving prison who have ongoing health vulnerabilities, including autistic people. The service starts working with people, including those who are autistic, before they leave prison and helps them to make the move to community-based health and care services that will provide the support that they need.

5.6.3 Locally, Wiltshire Police runs a scheme whereby an autistic or neurodivergent person carries an autism alert card so that police officers or other professionals or members of the community are advised that a person may have communication needs, or need some extra time or help in certain situations.

5.6.4 One of the BSW roadmap priorities is to develop community forensic assessment and treatment services in Wiltshire and Swindon.

Appendix 1 – alignment of priorities

The table below shows the priorities within the National Autism Strategy, our BSW roadmap priorities, Wiltshire SEND strategy priorities, and priorities identified by autistic adults and children and young people with autism and their families in Wiltshire.

National themes	BSW roadmap	Wiltshire SEND strategy	Wiltshire priorities
 <ul style="list-style-type: none"> • improving understanding and acceptance of autism within society • improving autistic children and young people’s access to education, and supporting positive transitions into adulthood • supporting more autistic people into employment • tackling health and care inequalities for autistic people • building the right support in the community and supporting people in inpatient care • improving support within the criminal and youth justice systems 	 <ul style="list-style-type: none"> • Recruitment of BSW programme lead. • Community forensic assessment service - Swindon and Wiltshire • Adult autism assessment service (levelling up Swindon) • ASC-friendly environments – expert-by-experience-led project. • CYP ASC transformation – investment into autism diagnosis. 	 <ul style="list-style-type: none"> • Developing holistic plans with children/young people • Inclusion and removing exclusion in education • Inclusion and wellbeing in the community • Improving the range and quality of provision • Progress and attainment • Well-planned transitions 	 <ul style="list-style-type: none"> • Inclusion in education & wider community • Raising awareness about autism • Improving support around practical and emotional life skills • Supporting autistic people into employment • Improve range of independent living options • Creating more social opportunities for autistic people • Creating channels of engagement that work for autistic people