Wokingham Area All-age Autism Strategy 2024 – 2029





and Berkshire West Integrated Care Board



Wokingham

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Introduction

This All-age Autism Strategy sets out a shared vision and direction for local health, care and education partners in supporting autistic people living in Wokingham borough. It is based on input from many local stakeholders, and sets out our vision, the context, our shared commitment, and the priorities we will focus on. It has been developed alongside Wokingham's SEND & Inclusion Strategy for 2024-29; there is a statutory requirement to have two separate documents, but these will be governed and delivered as two parts of an integrated and connected whole.

The Autism Act 2009 was the first of its kind, requiring the Government to have a strategy for improving the experiences of autistic adults, with guidance to councils and local partners. In 2021, the national strategy became all-age. The Act was driven by extensive evidence that autistic people face many barriers to access the right support at the right time, including access to diagnosis and support before a crisis. Autistic people as a population experience poorer life and health outcomes, have shorter life expectancies, and face many barriers day-to-day. We know this is reflected in people's experiences locally. With both the local population growing and awareness of autism increasing, we can also expect that there will be more autistic people living in the borough. Society's understanding of autism is changing rapidly, with the hugely positive impact of learning more from autistic people themselves about the richness and diversity of their experiences, gifts and strengths.

Whilst there has been progress, we recognise there is a long way to go to achieve our vision:

'For Wokingham borough to be a community where all autistic people, including those who selfidentify, as well as those who are possibly autistic:

- feel heard and understood, safe and secure, valued and included

- have the opportunity and support to do the things that matter to them and to reach their full potential, with the confidence to be themselves

- have the best possible start in life, living healthy and happier lives for longer, with support when they need it.'

We are fortunate in Wokingham borough to have many individuals, groups, and organisations committed to improving the life chances and experiences of autistic people. We are grateful to everyone who has inputted into the development of this strategy. Working collaboratively will be key to its success and we are committed to facilitating this.

The remit of this strategy is improving outcomes for all autistic people, including those who selfidentify, as well as those who are possibly autistic. There is growing public and system-wide support for taking a broader approach focused on neurodiversity, although this is not yet reflected in national strategy, policy frameworks and associated plans and resourcing. We will keep this under review and aim to broaden our scope in future. In the meantime, we will take a broad, neuroinclusive approach wherever possible, recognising that many autistic people are neurodivergent in multiple ways and that action we take as part of this strategy can positively impact people who are neurodivergent in other ways too.

Everyone is different and has their own preferences for language, so it is best to follow an individual's lead. This might include 'identity-first' language, e.g. 'I'm autistic', or 'person-first' language, e.g. 'I have autism'. For the purposes of this strategy, we are using the term 'autistic people' because this is preferred by most autistic people.¹ We are also using this term to refer to everyone to whom this strategy applies, including those who self-identify, as well as those who are possibly autistic.

As local education, health and care system partners, it is essential that we take a shared approach to improving access to the right support at the right time and work collaboratively to reduce inequalities and improve outcomes. We know this will not be achieved quickly, but that it is possible with shared leadership across the system over time and by building on progress. This strategy is jointly owned by the partnership – we thank our key partners to date for their role in developing this collectively and commitment to working together to deliver progress.

As part of this strategy, we outline our plan to continually review our progress, together with our local partners and guided by the diverse perspectives of autistic people locally. We will seek to broaden the partnership too, to ensure representation from all stakeholders. To get involved or find out more, please get in touch at <u>autismstrategy@wokingham.gov.uk</u>.

WBC Executive signature

BOB ICB Executive signature

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Buckinghamshire, Oxfordshire and Berkshire West **Integrated Care Board**

Cllr David Hare Executive Member for Health, Well-Being and Adult Services Wokingham Borough Council

¹ National Autistic Society (2023) How to talk and write about autism [Online] Available at: <u>https://www.autism.org.uk/contact-us/media-enquiries/how-to-talk-and-write-about-autism</u>

The development of this strategy

This strategy has been developed through the committed work of a wide range of stakeholders.

It reflects extensive work that was started in the spring/summer of 2020 and 2021, to co-produce a draft Adults' strategy. This included a period of engagement led by local organisation Promise Inclusion, including a survey with 139 responses from autistic people or on behalf of autistic people. This was followed by an extensive series of meetings of the Autism Project Group which included autistic adults, parents, carers and colleagues from a range of statutory services and community-led provision, and other local partners.

Reflecting the latest national strategy and in response to perspectives shared locally, we have now developed this into an all-age strategy. In doing so, we have incorporated themes from the Annual SEND Surveys produced by SEND Voices in summer 2022 and 2023 (available in the appendices) and perspectives shared by autistic children, young people, families and carers at events during 2023-24. This strategy reflects and is reflected by the SEND and Inclusion Strategy – which sets out a collective vision and direction of travel for Wokingham's SEND system serving children and young people 0-25 years with Special Educational Needs and Disabilities – co-produced with partners and people with lived experience in 2023-2024. These strategies are closely linked and we will develop the accompanying action plans jointly and steer progress and oversight through the multi-agency SEND Strategic Partnership Board.

The strategy also incorporates themes and experiences shared as part of the *Social Care Futures* movement for change building locally. The charter² – signed up to by Wokingham Borough Council's full council in 2024 - sets out a vision for social care in the borough, of finding a way to ensure people who draw on social care support are central to the decisions being made about their support, sharing power as equals and enabling everyone to live *'gloriously ordinary lives'*.

This strategy includes a commitment to establishing an Autism Partnership to facilitate an ongoing approach to incorporating the diverse perspectives and experiences of autistic people of all ages locally, to shape the development and delivery of the action plan. We are grateful to the many passionate individuals locally – especially autistic people, families, friends and carers - who have been instrumental in driving this progress and know that continuing to work together will be critical to success.

²Wokingham Borough Council (2024) Signing up to a new future for adult social care [online] Available at: <u>https://wokingham.gov.uk/news/2024/signing-new-future-for-adult-social-care</u>

What is autism and the scope of this strategy

Autism

The definition of autism has changed over the decades and is likely to change in future years as we develop our understanding, people's perspectives continue to develop, and some aspects continue to be subject to debate. Autism is a lifelong difference in brain functioning that affects how people perceive, communicate, and interact with and experience the world around them and others. It is considered a developmental spectrum condition because of the broad range of ways it can impact on people and the different levels of support people may need.³ The diagnostic criteria include social communication and interaction challenges, and repetitive and restrictive patterns of behaviour and interests.⁴

Everyone is different, and there are a wide variety of experiences amongst autistic people. Common differences and challenges often relate to: socialising; coping with new, unfamiliar, and unexpected situations; communicating, including differences in speech and language; and processing sensory inputs including sounds, lights, touch, and smells. Intense and highly focused interests can be a huge source of joy.⁵ Some common autistic strengths are: attention to detail; visual perception; creative and artistic talents; mathematical and technical abilities; interests or expertise in 'niche' areas; and character strengths such as honesty and loyalty.⁶

Around one in four autistic people speak no or few words and some autistic people may stop speaking during times of stress and anxiety⁷. A marked avoidance of demands is something experienced by and observed in some autistic people. This is often thought to be driven by anxiety or by intolerance of uncertainty (needing to know what is going to happen in order to feel calm)⁸. It can be a hidden or invisible disability, impacting people's day to day lives. Anyone can be autistic, and research currently suggests more than 1% of the general population⁹ are autistic. It is currently under-recognised in women and girls¹⁰ and amongst people from ethnic minority groups¹¹. We know there are likely to be many unidentified adults, as is reflected in local data. Improving people's understanding of autism in all its diversity is key to improving outcomes.

Co-occurring conditions

Autism is associated with various co-occurring conditions, which can mean that it is less likely to be diagnosed, leading to inequalities in access to health services and care.¹² Autism is not a learning disability or a mental health condition, and co-occurring conditions include⁵:

- A learning disability one in three people with a learning disability are also autistic, and • around 40% of autistic people have a learning disability¹³
- Other neurodevelopmental conditions over a third of autistic people also have ADHD¹⁴

* National Autistic Society (2024) Demand Avoidance [online] Available at: https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance

National Autistic Society (2020) What is Autism? [online] Available at: https://www.autism.org.uk/advice-and-guidance/what-is-autism?

National Autistic Society (2020) Diagnostic Criteria [online] Available at: https://www.autism.org.uk/advice-and-guidance/topics/diagnostic-criteria/all-audiences Ambitious About Autism (2022) What is Autism [online] Available at: https://www.ambitiousaboutautism.org.uk/information-about-autism/understanding-autism/what-is-autism

Autistica (2019) Focus on strengths as well as challenges [online] Available at: https://www.autistica.org.uk/news/focus-on-strengths-and-challenges

Autistica (2023) Signs and symptoms of autism [online] available at: https://www.autistica.org.uk/what-is-autism/what-is-autism/signs-and-symptoms-of-autism

National Autistic Society (2020) What is Autism? [online] Available at: https://www.autism.org.uk/advice-and-guidance/what-is-autism ¹⁰ National Autistic Society (2020) Autistic women and girls [online] Available at: https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls

¹¹ National Autistic Society (2023) Autism and BAME people [online] Available at: <u>https://www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-bame-people</u> ¹² World Health Organisation (2017) Autism Spectrum Disorders [online] Available at: <u>https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders</u> 13 Autistica (2023) Learning disability and autism [online] Available at: https://www.autistica.org.uk/what-is-autism/signs-and-symptoms/learning-disability-and-autism

¹⁴ Rong Y, Yang C-J, Jin Y, Wang Y. Prevalence of attention-deficit/hyperactivity disorder in individuals with autism spectrum disorder: a meta-analysis. Res Autism Spectr Disord. (2021) 83:101759. 10.1016/j.rasd.2021.101759 [accessed online, via google scholar)

- Mental health conditions such as anxiety and depression are very common¹⁵
- Acute mental illness up to 10% of adults in inpatient settings are autistic¹⁶
- Physical conditions, including gastro-intestinal and auto-immune conditions¹¹

Understanding and partnership working is therefore critical to identify and support autistic people.

Neurodiversity

The term neurodiversity refers to the natural variations in how our brains work, framing neurodivergence in terms of difference rather than deficits. There is growing support for this paradigm, which views neurodiversity as a form of human diversity subject to the same dynamics as other forms of diversity, including dynamics of power and oppression.¹⁷ For example the 'double empathy problem' theory highlights how communication challenges can be mutual, as when people with very different experiences of the world interact with one another, they can struggle to empathise with each other.¹⁸ Autism is understood as a form of neurodivergence, alongside other conditions including ADHD, Dyslexia, and Dyspraxia. Many people have more than one form of neurodivergence and there are areas of overlap in presenting needs, for example relating to executive functioning, as well as in strengths, like creativity.¹⁹ As set out in the introduction, whilst the remit of this strategy is improving outcomes for autistic people, we will take a broad, neuroinclusive approach wherever possible

Breadth of experiences and needs

People's experiences and needs for support are highly varied, reflecting the diversity in how autism impacts people, as well as the presence and nature of co-occurring conditions and people's broader life circumstances. For some children, their autistic traits are recognised early, leading to accessing support including for other co-occurring conditions such as a learning disability. For other children and adults, their traits are picked up on at a later stage, sometimes after struggles in areas such as schooling, employment, and often following periods of mental distress. For many people, the identification process can help them to make sense of their experiences and some of the challenges they face. This can also help them to access support, including adjustments at school or work and resources such as educational workshops with peers. Some adults self-identify as autistic later in life, and with the support of resources including online peer communities, this journey can be key to unlocking their ability to thrive. Others have autistic traits and do not seek or get the opportunity to explore whether they are autistic. This strategy is aimed at improving outcomes for everyone and will align with other strategies and plans in place across the system, prioritising gaps.

Family, friends, and carers

Many autistic people need some support with certain activities or situations, which they may draw on from the people around them day-to-day. Some autistic people may also need to access paid care and support long-term to thrive. Throughout life, autistic people will draw on their natural support networks, as we all do. For some autistic people, this may extend to family members and

¹⁵ Autistica (2019) Autistica Action Briefing: Other Co-Occurring Conditions [online] Available at: https://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Other-Co-Occurringonditions.pdf Autistica (2019) Autistica Action Briefing: Adult Mental Health [online] Available at: https://www.autistica.org.uk/downloads/files/Autistic-Action-Briefing-Adult-Mental-Health.pdf

¹⁷ Autistic UK (2020) Neurodiversity [online] Available at: <u>https://www.autisticuk.org/neurodiversity</u>

⁸ National Autistic Society (2018) The double empathy problem [online] Available at: https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy

¹⁹ ADHD Aware (2022) Neurodevelopmental Conditions [online] Available at: https://adhdaware.org.uk/what-is-adhd/neurodiversity-and-other-conditions/

friends taking on a caring role in addition to their other roles. Whilst this strategy focuses on autistic people themselves, it will be linked to strategies and plans supporting carers.

Why a Wokingham Autism Strategy is needed

National data tells us that autistic people generally experience poorer health and wellbeing outcomes than the wider population. Through our engagement with local autistic people and their families and other key stakeholders, we know that autistic people locally continue to face significant barriers to accessing the right support at the right time. Meanwhile, the need for support is growing as our population grows and awareness of autism increases. Progress will require the action of multiple stakeholders, nationally, regionally, and locally, working with autistic people and their families.

National context

The National strategy for autistic children, young people, and adults: 2021 to 2026²⁰ builds on previous strategies since the 2009 Autism Act and associated statutory guidance to local authorities and NHS bodies. Key legislation such as The Equality Act 2010, Care Act 2014 and Health and Social Care Act 2022 have also specified action to address inequalities facing autistic people. As commissioners of the local health and care system, we hold statutory duties to steward progress more broadly, in addition to within our own organisations. In summary:

	Local authority (LA), Integrated Care Board (ICB) & Health and Wellbeing Board (HWB)
Accountability	Appoint commissioning lead (LA) Review plan annually (HWB)
Strategy	Develop a joint strategy based on JSNA data/Autism Needs Assessment with stakeholders, including the views of local people with autism and carers, with stakeholders (LA with ICB)
Partnerships	Ensure meaningful local arrangement/s in place , with senior LA & NHS input & autistic people & families (LA with ICB)
Services oversight	Ensure general autism awareness & data collection is in place (LA & ICB) Service specifications to include requirement to demonstrate how reasonable adjustments will be made (LA & ICB)
Training oversight	Ensure staff have appropriate training, enhanced for social care assessors & providers (LA & ICB) Lead on local Oliver McGowan training for CQC registered providers capacity & plans (ICB)
Expertise oversight	Ensure staff carrying out assessments have the knowledge/access to expertise required (LA & ICB) Appoint clinical lead to develop diagnostic and assessment services (ICB)

Local context

The evidence base for this strategy is provided in the Wokingham Autism Needs Assessment and key local engagement reports, available in the appendices. This data informs each of our priority areas for action and a snapshot is provided under each priority area.

²⁰ Department of Health and Social Care and Department for Education (2021) The national strategy for autistic children, young people and adults: 2021 to 2026 [online] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

Our principles

We will work together and alongside others locally, including partner organisations from across the system and autistic people, towards our shared vision:

'For Wokingham borough to be a community where all autistic people, including those who self-identify, as well as those who are possibly autistic:

- feel heard and understood, safe and secure, valued and included

- have the opportunity and support to do the things that matter to them and to reach their full potential, with the confidence to be themselves

- have the best possible start in life, living healthy and happier lives for longer, with support when they need it.'

In working together, we will follow these principles:

1. We will be guided by autistic people and their families

We will establish an Autism Partnership to co-develop plans and drive progress, ensuring that we are led by local autistic people of all ages and their families.

The Partnership will proactively facilitate wide input from autistic people and their networks, reflective of the broad autism spectrum as well as the diverse Wokingham borough population. This is key to ensure actions we take as respective organisations, as a health, care and education system, and as a partnership, lead to tangible improvements in the experiences of *all* autistic people locally.

We will ensure we consider the views and guidance of other stakeholders too, for example working collaboratively with professionals from across the system with autism expertise.

2. We will be accountable for our progress

We recognise that there is a lot of work for us to do together across the local system, to achieve this vision. We will focus our joint action plan each year, to drive and deliver progress towards this vision in specific areas, aligned to the ambitions identified in this long-term strategy. We will review our progress with stakeholders and agree the next areas we are going to focus efforts on, to ensure that we are making tangible progress each year.

We have established an Autism Joint Planning Group – chaired by a senior Wokingham Borough Council representative and with multi-agency representation – to drive this action plan development and delivery and secure decisions through relevant governance structures. It will have representation from the Autism Partnership and will report into the SEND Strategic Partnership Board. Alongside the SEND and Inclusion Strategy, this strategy and associated action plans will be published on the SEND Local Offer and Wokingham Borough Council websites. An annual progress update to the Health and Wellbeing Board will also be developed in collaboration with key stakeholders and partners and be made publicly available.

3. We will lead change and facilitate collective action across the system

We will strengthen how we work on complex issues requiring a collective approach, including with organisations providing services across the wider system. This will include regularly listening to stakeholders through various means, including Provider Forums.

As part of this we will seek out ways to tackle key operational barriers to joint working, for example to improve shared data available to us and to improve our mechanisms for multiagency decision-making and accountability and joint commissioning.

4. We will resource collaboration

We have appointed a Commissioning Manager, Autism Lead and set aside resources specifically to support the delivery of this strategy and its action plan in collaboration with partners and local residents.

There will also be implications for respective organisations, for example adaptations to services and investment in new initiatives. Specifics will be developed with the relevant leads, with decisions made through respective structures in line with available resources.

5. We won't wait to get involved

We recognise that autistic people require widely varying levels of support and that needs will change with age, life events and other factors. Key to this strategy will be working together to prevent unnecessary delays to accessing the right support, at the right time, from the right people. Support will be needs-led not diagnosis-led.

We don't want autistic people to have to wait until they've had a formal diagnosis to receive support and we will therefore ensure some intervention is provided at the earliest stage possible; this will mean that some people will never need to progress to a formal diagnosis or assessment as their needs will have been addressed at an earlier stage.

Whilst this principle applies to support at an early stage, we must also ensure that people with higher levels of need can access specialist support when required; some services (particularly those serving more complex needs) will, therefore, continue to prioritise or only serve those with a diagnosis.

Cross-cutting areas of focus

The following will be areas of focus across all the priority areas outlined in this strategy:

- A) Equality, diversity, and inclusion
- B) Building blocks of Health and Wellbeing
- C) Carers

Equality, diversity, and inclusion

With each priority area, we will ensure that we are improving opportunities and outcomes for all autistic people locally. This will include a focus on the nine protected characteristics outlined in the Equality Act including sex and race, as well as other priorities areas including socio-economic disadvantage. We will work to understand needs, develop specific initiatives as required, and implement measures for tracking progress with autistic people facing the worst outcomes, and report on and monitor this. This work will contribute to reducing the unfair and preventable differences that we know exist between communities within the borough.

In accordance with the social model of disability²¹, we know that key to improving outcomes for autistic people is tackling societal barriers. We need to proactively adapt our environments so they work for many different brains, creating cultures where everyone can feel safe, a sense of belonging and can draw on their strengths and achieve their potential. This includes Reasonable and Anticipatory Adjustments, set out in the Equality Act 2010^{22} .

Building blocks of Health and Wellbeing

 We^{23} are working towards becoming a 'Marmot Borough'²⁴ – joining over 50 places recognising that to create a community where everybody can thrive, we need all the right building blocks of health and wellbeing in place. A Marmot approach improves outcomes for everyone, but with a focus on those who have the greatest needs and the worst outcomes. The environment we live in and the opportunities we have throughout life play an important role in determining whether people and communities flourish.

These "Building Blocks of Health and Wellbeing" are shown in the figure below²⁵.

²¹ Scope (2024) The Social Model of Disability [Online] Available at: https://www.scope.org.uk/social-model-of-disability

²² Public Health England (2020) Reasonable adjustments: A legal duty [online] Available at: https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty ²³ Wokingham Borough Council (2024) Council minutes 18/1/2024 - Motion 511 submitted by Prue Bray [online] Available at:

https://wokingham.moderngov.co.uk/ieListDocuments.aspx?CLd=131&MID=4720#AI42240 ²⁴ The Institute of Health Equity (2024) Marmot Places: the areas taking a proactive local approach to health inequalities [online] Available at:

ttps://www.instituteofhealthequity.org/taking-action/marmot-place

https://www.instituteomeatineguity.org/taking-action/maintoc-proces

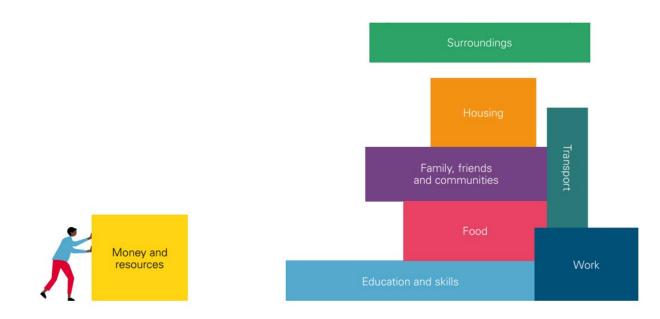


Figure 1 – The Building Blocks of Health, the Health Foundation

To create a society where everybody, including autistic people, can thrive, we need all of the right building blocks in place: access to secure housing, good jobs with fair pay, quality education and much more. These building blocks underpin this strategy and our action plan will include links to related strategies and action plans aimed at particular 'blocks', guided by the Marmot principles.

Carers

The term 'carer' refers to people acting in a caring role towards someone in addition to their relationship as a parent, partner, child, neighbour, or friend. Every priority area will impact carers of autistic people and just as carers have played a key role in the development of this strategy, we will ensure they are involved in shaping and overseeing progress going forward. We will link this work to other specific strategies and initiatives to address the specific needs of carers, ensuring carers of autistic people are represented, there is feedback and that we monitor progress.

Priorities and ambitions

Strategic priorities

Within this strategy our priorities for action are structured in line with the national strategy priority areas, although broadened to reflect our local context, informed by the perspectives of local autistic people and their families.

The priority areas are as follows:

- 1. Neuro-inclusive communities, including local facilities and services, and employers
- 2. Identification, and improving health outcomes, including diagnostic pathways
- 3. Start well, including education and transition to adulthood
- **4.** Live well and age well, including community support, employment, adult social care, and housing
- 5. Emotional wellbeing and mental health and crisis support
- 6. Safer communities and the Criminal Justice System

Each priority area includes the ambitions we will work on during this strategy period. Accompanying deliverables will be set out in the action plan, developed with partners from across the broader local system and guided by autistic people and family carers.

The local snapshot data provided for each priority area is taken from the Wokingham Autism Needs Assessment (available in the appendices). The quotes are from the Autism Strategy Engagement Report 2022, the SEND Surveys 2022/3 (available in the appendices) and feedback in 23/24 and 24/25.

Alignment with the SEND & Inclusion Strategy priorities and ambitions

This All-Age Autism Strategy has been developed alongside Wokingham's SEND & Inclusion Strategy for 2024-29; there is a statutory requirement to have two separate documents, but these will be governed and delivered as two parts of an integrated and connected whole.

Whilst there is common ground and consistency between the two Strategies, they have a somewhat different scope in that the Autism Strategy covers people of all-ages and focuses specifically on autistic people, whereas the SEND & Inclusion Strategy covers the 0-25yrs age range and includes children and young people who are not autistic. Consequently the priorities are organised and presented somewhat differently; the Autism Strategy follows the structure of the national strategy whereas the SEND & Inclusion Strategy has been developed in response to Wokingham's local context and has identified the following six strategic priorities:

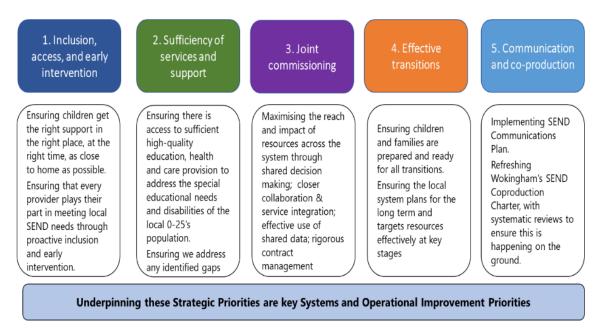


Figure 2 - Wokingham's SEND & Inclusion Strategy - Six Strategic Priorities

Action plans and accountability

The action plans and workstreams that will deliver the objectives under both strategies will be integrated as far as possible and will be delivered through the SEND Transformation Programme and governed by the SEND Strategic Partnership Board. These will be published and updated on an annual basis.

Aspects of this All-Age Autism Strategy focused on adults over 25 – and which therefore fall outside the scope of the SEND & Inclusion Strategy – will be led through other relevant substructures of the Health and Wellbeing Board. They will also be aligned to other strategies and action plans and governance mechanisms, including the Adult Social Care Strategy and the Learning Disability Strategy and broader strategies and action plans relating to planning, housing, transport and community safety for example.

The multi-agency Autism Joint Planning Group will ensure a coordinated approach and report into the multi-agency SEND Strategic Partnership Board and the multi-agency Health and Wellbeing Board.

1: Neuro-inclusive communities

Whilst public awareness and understanding of autism is growing, we know that there is a long way to go for all autistic people to feel heard, understood, included and able to thrive.

We know there are a lot of misconceptions about what autism is and how differently it presents in different people, which can make it harder for people to identify it. This can lead to people being misunderstood and not accessing the right support, at the right time. We know too that when people are exploring their own needs or those of their loved ones, they find it difficult to access information about what the next step is and support available.

Autistic people face more barriers in their day to day lives, for example, in using public transport, going shopping, or filling out forms. We know there is much more that can be done to adapt our everyday environments, so they work better for everyone.

There are strengths for us to build on locally too. We have many individuals, groups, and organisations passionate about improving the life chances and experiences of autistic people. For example, there are local employers taking action to develop neuro-inclusive environments that celebrate autistic strengths, with the leadership of autistic employees.

Key data – Wokingham	Wokingham's population grew by 15% between 2011 and 2021 and will likely keep growing into the future.
Autism Needs Assessment	 Based on the current national prevalence rate used of 1.1%, we would expect there to be nearly 2,000 autistic people living locally. However, this rate needs updating, with research indicating it should be set higher.²⁶ We know that 2,459 borough residents have autism on their GP records. This is skewed towards the younger population and so we know this will exclude many unidentified autistic adults locally, as well as some children. Of these, 14.3% are from an Asian, Black, or Other ethnic minority group, which is under representative of the proportion of people in the overall
	Wokingham Borough population from these ethnic minority groups (20%).
Key gaps according to autistic people &	74% of parents said it was not very easy, difficult, or very difficult to find information. (SEND Survey, 2023 – over 50% parents of autistic children) Respondents advised that most facilities and services, including Council
families	offices, schools, places of religion and sports facilities were not autism friendly. (Autism Strategy Engagement Report, 2020)

A local snapshot

²⁶ National Autistic Society (2020) What is Autism? [online] Available at: <u>https://www.autism.org.uk/advice-and-guidance/what-is-autism</u>

Our ambitions

To work towards Wokingham borough being a great place for autistic people to live, we will:

- 1. Raise public awareness amongst all ages, of autism and the breadth of ways it can present, and in the context of neurodiversity. Alongside this improve access to information and support, so all autistic people, families, carers, and communities can better understand autism and access support.
- 2. Take action to embed consistently neuro-inclusive practices across our respective organisations, including raising awareness and knowledge amongst professionals and as employers through our People Strategies and associated action plans.
- 3. Work in partnership with local facilities, services, community groups and businesses to embed consistently neuro-inclusive practices and to develop opportunities, including volunteering and paid employment.

2: Identification, and improving health outcomes

Identification of autism is increasing as awareness grows in how differently it can present, particularly amongst women and girls. This is to be celebrated, as more autistic people will have the opportunity to understand themselves and their experiences, including their own unique strengths. Identification is a critical first step in preventing autistic people's needs being overlooked or misunderstood, averting crises, and improving outcomes. There are still significant disparities to address, as knowledge is variable across the system and population.

People seeking an NHS diagnostic assessment face multiple year waits, as the increase in referrals continues to outpace investment. People are increasingly turning to private providers or self-identifying after extensive research. We are working as a system to review pathways for diagnosis and ensure timely access to support. This includes improving access to assessing, understanding and supporting people's neurodiversity.

Autistic people generally experience poorer health outcomes than the wider population. Autistic adults without a learning disability are 9 times more likely to die from suicide, while autistic people with learning disabilities are at the highest risk of a range of physical health conditions. All autistic people's health risks are amplified by social determinants of ill health. Autistic people are disproportionately affected by unemployment, poverty, abuse, trauma, and social stigma. For autistic people who are marginalised in other ways – such as those in ethnic minority groups, identifying as LGBTQ+ – this effect is compounded even further.²⁷

We also know that autistic people face barriers in using health services and there is much work to do to make them more neuro-inclusive. There are areas of strength to build on here too, with examples of best practice emerging from a range of local health settings.

Key data on need	The number of people referred to autism diagnostic pathways is increasing. The data available across Berkshire West – including Wokingham, Reading and West Berkshire populations – shows monthly referrals for all ages have risen from 60 in June 2019 to 360 in June 2023. Of the 360, 90% are 0-17 year olds.
Key messages from	"GP wouldn't refer me to start with. Said I didn't 'strike' him as autistic" (Autism Strategy Engagement Report, 2020)
autistic people & families	80% of respondents said they accessed private healthcare services in the last 12 months because waiting lists were too long (cited 3 years for a diagnostic assessment) (SEND Survey, 2023)

A local snapshot

²⁷ Autistica (2023) Health Checks Plan [online] Available at: <u>https://www.autistica.org.uk/downloads/files/Health-Checks-Plan.pdf</u>

Our ambitions

To work towards all autistic people getting to live healthy lives for longer and getting access to the right support at the right time, we will:

- 1. Develop our pathways and services so that all autistic children and adults can access support at the earliest opportunity, led by their individual needs. This includes support to people exploring whether they are autistic.
- 2. Facilitate partnership-working to proactively improve health and wellbeing including through early support - to improve outcomes for all autistic people and with a particular focus on those facing the worst outcomes taking an equality, diversity and inclusion approach.
- 3. Develop consistently neuro-inclusive practices across all health services and awareness of co-occurring health conditions, to improve experiences and outcomes for all autistic people.

3: Start well

As awareness and acceptance of autism and other neurodivergent conditions has grown, a needs-led approach is increasingly being adopted, to tailor support to meet individuals' needs. However, there is a long way to go, and we know that too many children are not getting the opportunities and the support they need to thrive in childhood and beyond.

We know that there is much work to do to ensure that the Special Educational Needs and Disability (SEND) system can enable all autistic children and adults up to age 25 to access the right support, within and outside school. Key to this is increasing provision to match demand. Whilst schools are working hard to make adaptations so that all autistic children can reach their potential, there is a need for more consistent resourcing and practicing of neuro-inclusive approaches. As part of Wokingham's SEND Transformation Programme which is overseen by the Department for Education, we are working with our local partners to address these challenges, including opening two new SEN Free schools, developing additional specialist Autism provision within mainstream schools and ensuring all mainstream schools offer more consistent high quality support.

Improving support and opportunities for autistic children preparing for adulthood is key. This includes developing education, training and employment routes and support, as well as preparing for transition to adult services, including adult social care. This is also critical for children whose needs will not meet the eligibility threshold for adult social care support.

As with all service areas, there is scope to make improvements across children's services to ensure they are neuro-inclusive and well equipped to support autistic children, parents, and caregivers. We have key assets here too, including specialist autism support.

Key data	There are 1,505 borough residents ages 0-19 with autism on their GP record,
on need	three times higher than the national prevalence rates would indicate. ²⁸
	There are 649 children with autism identified on an Education, Health, and Care Plan (EHCP) who live in Wokingham borough, as well as 458 children who receive additional SEN support in Wokingham borough schools. This is a total of 1,107 autistic children known to education services. Almost 80% of children with autism identified on EHCPs are male, and 66% of autistic children receiving SEN support are male.
Кеу	"Support is inconsistent and not good enough, which results in anxiety induced
messages	absences. A lot more can be done but it's a constant battle." (SEND Survey,
from	2023).
autistic	
people &	"Mainstream schools are the place where autism awareness really needs to
families	start." (Autism Strategy Engagement Report, 2020)

²⁸ See Autism Needs Assessment in the appendices for full source information and context - this could indicate that the prevalence in the borough may be higher than the national prevalence rate, however it could also reflect a higher rate of detection or be a result of biases within the data and therefore this number should be interpreted with caution.

Our ambitions

To work towards all autistic children getting the best start in life, we will:

- 1. Support all educational settings to become more neuro-inclusive environments by design, and to implement needs-led support at the earliest opportunity.
- 2. Increase and improve provision through the Special Educational Needs and Disability (SEND) system, including specialist support and settings.
- 3. Increase opportunities and support for autistic children growing into adulthood, including training and employment. This will include a particular focus on children whose needs do not meet the eligibility threshold for drawing on support from adult social care.
- 4. Embed consistently neuro-inclusive and trauma-informed practices children's social care services, so they are well-equipped to support autistic children, parents, and caregivers.

4: Live well and age well

With autism and other neurodivergent conditions becoming better understood, late identification amongst adults is increasing. Whilst this is to be celebrated, it can be a complex experience and often follows periods of increased struggle. Whilst there is growing understanding of the difficulties many autistic adults experience day to day, many continue to face barriers to accessing the right support at the right time and especially at times of significant change in their lives. Autistic adults also face a stark employment gap and whilst neuro-inclusive practices amongst employers are increasing, there is a long way to go.

The right support at the right time can make a huge difference in supporting autistic people to better understand themselves, their needs and their strengths, and to shape their lives in a way that supports their flourishing and wellbeing. More neuro-inclusive environments – described more in priority areas 1 & 2 – have a critical role to play in facilitating this too.

We know there are likely to be many older adults with autistic traits who are not identified as autistic, who may be accessing various forms of support as they age or their life circumstances change. Awareness-raising and developing more neuro-inclusive practices and settings will benefit them too.

There are strengths for us to build on, with many local early intervention and prevention services including but not limited to targeted community and voluntary sector services. We know autistic people are accessing this support, and there is scope to develop this further.

Some autistic adults also need support from statutory services to live their lives well, for example housing and/or social care support and face barriers in accessing them. We recognise the need for change and are working towards our Social Care Futures²⁹ vision of:

everyone being able to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing things that matter to us.

A local snapshot

Key data on need	There are around 1,100 borough residents ages 18+ with autism on their GP record, compared with a national prevalence rate estimate of 1,501 adults 18+.
	In the past year (Feb 23-Jan 24), Optalis Supported Employment Services have supported 78 autistic adults, including 45 into paid employment.
	864 people aged 18-64 are drawing on adult social care support, of whom 485 have a learning disability ³⁰ and 80 have autism without a co-occurring learning disability. There are currently 178 autistic children over 16 who will likely need to draw on adult social care support.

²⁹ https://www.wokingham.gov.uk/news/2023/looking-future-adult-social-care-wokingham-borough

³⁰ We need to improve our data to capture the number of people with a learning disability with co-occurring autism - based on national data we would expect this to be 160 people.

	Between September 22-23 15 autistic adults sought support from the WBC Housing Needs and Options Service.
Key messages from	"I would like there to be more opportunities to meet people like me" (Autistic adult, engagement 2022/3)
autistic people & families	"People are assuming and not always recognising needs and are thinking that autistic and neurodivergent conditions are either learning disabilities or mental health conditionswe need specialist employment support" (Autistic adult, engagement 2022/3)
	Half of respondents had difficulties managing bills, doing housework, shopping for food and cooking. Housing issues shared included living in an isolated area that is too far from public transport and issues with noise including from neighbours. (Autism Strategy Engagement Report, 2020)

Our ambitions

To work towards all autistic adults getting to live and age well, we will:

- 1. Work in partnership with commissioned community and voluntary sector services, and other community groups and organisations and other local partners, to further develop support available to all autistic adults. This includes employment support, social opportunities and practical help, designed with autistic people themselves.
- 2. Develop adult social care, with autistic people. This is to address gaps in provision and embed consistently neuro-inclusive practices across services. This will be aligned to other Adult Social Care initiatives and strategies, including Social Care Futures and the Adult Social Care Strategy.
- 3. Increase options available through the WBC Affordable Housing Strategy and embed neuro-inclusive practices across housing services, including through working with our registered providers and strengthening mechanisms for joint working across the Council, Health, and voluntary and community sector partners.

5: Emotional wellbeing and mental health and crisis support

As more people have shared their internal and day-to-day experiences of being autistic, there is increasing awareness about how it can impact emotional and social wellbeing. Girls and women especially more commonly mask their differences and their struggles.³¹

We know that whilst a quarter of the general population struggle with their mental health at some point in life, amongst autistic people this is much higher with almost 80% of autistic adults experiencing mental health issues during their lives. For many autistic people, mental illness can be more difficult to recognise and treat effectively.³² It is key that preventative support is in place, enabling autistic people to access support earlier and prevent a crisis.

Many people identify their autism via mental health services pathways, often after having experienced a period of crisis followed by treatment and sometimes a misdiagnosis. They may need their treatment to be changed altogether, or for adaptations to be put in place to support with their co-occurring conditions. Mental health teams locally are supporting increasing numbers of people – especially girls and women – with complex needs and dual diagnoses, some of whom identify as autistic and more of whom are suspected autistic although do not have a diagnosis. Too many autistic people continue to be admitted to inpatient services after reaching crisis point when this could have been prevented.

Work is already underway to address these challenges, including via Berkshire Health Foundation Trust's Community Mental Health Transformation programme and the jointly commissioned Emotional Wellbeing Hub to provide guidance for 0–19-year-olds.

Key data on need	In April to June 24, 29% of referrals to the Mental Health in Schools Team and 38% of referrals to the Emotional Wellbeing Hub were for children and young people with a diagnosis of Autism or on the diagnostic pathway.
	The Wokingham Integrated (with Berkshire Health Foundation Trust) Mental Health teams are supporting approximately 70 autistic adults, across the Community Mental Health Team, Mental Health Integrated Community Service and the Wokingham Recovery College (2023).
Key messages from autistic people &	"It's a maze of different services, abbreviations, professionals, wait times, forms. Absolutely baffling even to an educated and capable parent. Wait times are so long. My child has taken overdoses waiting for support." (SEND Survey, 2022)
families	"I get passed between mental health services and social care." (Autistic adult, engagement 22/23) 85% of respondents had a co-occurring mental health condition (Autism Strategy Engagement Report, 2020)

A local snapshot

 ³¹ Autistic Girls Network (2022) Autism, Girls, & Keeping it All Inside [online] Available at: https://autisticgirlsnetwork.org/keeping-it-all-inside.pdf
 ³² Autistica (2023) Autism and mental health – A guide to looking after your mind [online] Available at: https://www.autistica.org.uk/downloads/files/Mental-health-autism-E-LEAFLET.pdf

Our ambitions

To work towards ensuring autistic people can experience improved mental health and wellbeing, and can access the right crisis support at the right time, we will:

- 1. Tailor early mental health and wellbeing support for autistic people and their families, so people can better understand and embrace their autistic self, and so their needs, supportive strategies and helpful environments are understood to prevent reaching crisis.
- 2. Develop consistently neuro-inclusive practices across mental health services, leading to earlier identification and support, reduced misdiagnoses, and better treatment outcomes, including for autistic people with co-occurring mental health conditions. This includes approaches designed with autistic people and their families.
- 3. Strengthen joint working between education, health, social care and community and voluntary sector services, including developing suitable housing, family and community support and social care options, especially for people at risk of experiencing a crisis as well as following a crisis and for young people approaching adulthood.

6: Safer communities and the Criminal Justice System

All criminal justice professionals may come into contact with autistic people, many of whom may be undiagnosed/identified. It is therefore vital that these environments have a good understanding of autism and that we take coordinated action to prevent offending in the first place.

The National Autistic Society states that autistic people are more likely to be victims and witnesses of crime than offenders and we know some features of autism increase this risk.³³ We have therefore broadened this national priority area to include a focus on community safety, including building protective factors amongst autistic people themselves.

There are strengths in this area, with initiatives in place across the Criminal Justice System. Thames Valley Police have undertaken extensive training and the Probation Service have commissioned 1-1 support for people with a diagnosis and with suspected autism. There has been extensive training and development relating to SEND for the local partnership supporting children and they were awarded the Youth Justice SEND Quality Mark in 2023.

A local snapshot

Key data on	The Prevention and Youth Justice Service works with approximately 180
need	children per year and a one-month snapshot indicated half had SEN needs.
	There are approximately 50 adults on probation locally who declare a learning disability and/or a neurodivergent condition, including autism. WBC Adult Social Care teams work with approximately 5-10 autistic people a year who are involved with the Criminal Justice System.
Key	Survey respondents felt the autism awareness training that Thames Valley
messages from	Police had undergone has had a positive effect. (Autism Strategy Engagement Report, 2020)
autistic	
people &	"Young people in our group are especially concerned about bullying by peers
families	and are also feeling unsafe owing to criminal activity and anti-social behaviour near schools." (Group facilitator, engagement 2022/23)

³³ National Autistic Society (2023) [online] Criminal Justice – a guide for police officers and professionals. Available at: https://www.autism.org.uk/advice-and-guidance/topics/criminal-justice/criminal-justice/professionals.

Our ambitions:

To work towards reducing risks and increasing the safety and wellbeing of all autistic people and their families, we will:

- 1. Tackle bullying, anti-social behaviour, and criminal activity including sexual abuse, domestic abuse, hate crime, mate crime and exploitation, to reduce the risks to autistic people's safety and wellbeing as well as potential involvement in crime.
- 2. Build protective factors amongst autistic people themselves, including psychosocial education about relationships and how to raise concerns and online safety, alongside action to create more neuro-inclusive environments.
- Sustain effective partnership-working across the Criminal Justice System, to support autistic people – including those who are accused of or have committed crimes – to ensure access to appropriate support and to prevent offending and support rehabilitation.

Appendices

• Wokingham Autism Needs Assessment 23

o https://wokingham.berkshireobservatory.co.uk/needs-assessments-profile/

• SEND Annual Survey 2023

- <u>https://www.sendvoiceswokingham.org.uk/uploads/Annual%20SEND%20Survey%202023%20FINAL.pdf</u>
- Further annual surveys available here <u>https://www.sendvoiceswokingham.org.uk/-get-involved</u>
- Wokingham Area Send & Inclusion Strategy 2024-29
 - <u>https://www.wokingham.gov.uk/children-families-and-young-people/send-local-offer/about-send-local-offer/send-strategies/our-send-strategy</u>
- Buckinghamshire, Oxfordshire, and Berkshire West Integrated Care System Joint Forward Plan – Service Delivery Plans 2023
 - <u>https://www.bucksoxonberksw.icb.nhs.uk/media/2916/bob-joint-forward-plan-service-delivery-plans-june-2023.pdf</u> (pages 30, 31, 45-49)
- Berkshire Health Foundation Trust Neurodiversity Strategy
 - <u>https://www.berkshirehealthcare.nhs.uk/about-us/transformation-and-innovation-in-healthcare/service-transformation/neurodiversity-strategy/</u>

Further information

autismstrategy@wokingham.gov.uk

or

0118 974 6000 (Wokingham Borough Council customer services)

Support available

There are various services providing information, advice, and support locally, which the following autism-specific services can also support with navigating:

ASSIST Team

ASSIST@wokingham.gov.uk

0118 908 8002

ASD Family Help

Contact@asdfamilyhelp.org

07733 601 755

Autism Berkshire

contact@autismberkshire.org.uk

01189 594 594

Promise Inclusion (also part of the Carers Partnership)

admin@promiseinclusion.org

0300 777 8539

Located at the Wokingham Charity and Community Hub,

alongside other key services -

Waterford House, Erftstadt Court, Denmark St., Wokingham, RG40 2YF



ASD Family Help



