



Reading's **All Age Autism** Strategy 2022-2026



Our Vision



For all of Reading's autistic people
and their families and carers to feel
supported, included and be enabled to
live their best and healthiest lives through
awareness and support across the life course

The evidence base for this strategy sits within the All-Age Autism Needs Assessment and the two documents are intended to complement each other.

Contents

Our Vision	02
1.0 Introduction	04
2.0 What is Autism	05
2.1 Co-occurring conditions	07
3.0 Why a Reading Autism Strategy is needed	08
3.1 Our Local Plans and Strategies	10
4.0 National Prevalence	12
5.0 Local Context	13
5.1 How the strategy was shaped	13
5.2 Our Ambitions	15
6.0 Priorities	16
Priority 1 Improving awareness, understanding and acceptance of autism	17
Priority 2 Improving support and access to early years, education and supporting positive transitions and preparing for adulthood	21
Priority 3 Increasing employment, vocation and training opportunities autistic people	26
Priority 4 Better lives for autistic people – tackling health and care inequalities & building the right support in the community and supporting people in inpatient care	28
Priority 5 Housing and independent living	39
Priority 6 Keeping safe and the criminal justice system	42
Priority 7 Supporting families and carers of autistic people	46
7.0 Delivering our future priorities	50

Throughout this document, we have tried to use Identity-First language (i.e., 'autistic people' rather than 'people with autism') as an umbrella term for all autistic spectrum conditions and disorders, including Asperger Syndrome as it is acknowledged that for some, this is the preference of some autistic people. Where there is use of alternative language, this is because it is used in the national guidance, or the terminology is being cited from data provided in that format. It is acknowledged that these are not necessarily the terms everyone would choose. However, this strategy is intended to be inclusive to all those identifying with any of these terms, or related terms.

1.0 Introduction

Autism is a national priority. This Strategy has been brought together by a Steering group made up of autistic people, carers, professionals working with autistic people, members of the Autism Board and multidisciplinary professionals from across Reading's system to highlight our joint ambitions.

Those engaged throughout the development of this strategy:

- Autistic people, parents, carers
- Brighter Futures for Children
- Berkshire West Hub
- Reading Borough Council, Public Health Officers
- Reading Borough Council, Public Health Analyst
- Berkshire West Public Health
- Autism Berkshire / Parenting Special Children
- Reading Mencap
- Thames Valley Police
- Berkshire Health Foundation Trust (BHFT)
- Healthwatch Reading
- Reading Families Forum
- Talkback CAMEO
- Liaison and Diversion Service
- Probation Service
- Youth Offending Service
- The Department for Work and Pensions (DWP)
- Job Centre
- New Directions
- Other Employments related organisations
- Special United group
- Reading Autistic Families Together (RAFT)
- Compass Recovery College - Autistic adults
- Reading Families Forum - Attendees
- Autism Berkshire - Parents/Carers
- Engine Shed Session - Children/Young people
- Parenting Special Children (Auticulate)

Our ambition is to have a whole systems approach to ensure Reading is a more inclusive place to live and that autistic people can get the right support they need when they need it. This strategy and associated plans are for all autistic people in Reading, including those who support them.

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2.0 What is Autism?

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.¹ It is recognised as a difference, not a medical condition requiring a “cure”.² Autism is not a learning disability, although various reports indicate that approximately 4 in 10 autistic people have a learning disability³.⁴ Within this strategy, we also talk about neurodiversity.

Neurodiversity

Neurodiversity is the fact that all human beings vary in the way our brains work.

- Take in information in different ways
- Process it in different ways
- Thus, behave in different ways

The Neurodiversity Paradigm

1. Neurodiversity is naturally occurring
2. No one way of being is better than another
3. Neurodiversity operates like other equality diversity dimensions
4. Strength in diversity itself – collective not individual value

Professor Sue Watson



There is growing support for the Neurodiversity Paradigm, which frames all neurodivergence (such as autism, attention deficit hyperactivity disorder [ADHD] and dyslexia) as a positive and creative concept to be embraced rather than regarded as a psychological issue.⁵

Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives.

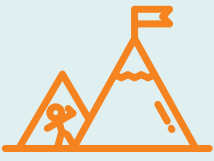
¹ National Autistic Society (2020). What is Autism? [online] Autism.org.uk. Available at: <https://www.autism.org.uk/advice-and-guidance/what-is-autism>.

² NHS (2019). What Is autism? [online] NHS. Available at: <https://www.nhs.uk/conditions/autism/what-is-autism/> [Accessed Dec. 2021].

³ NICE (2018). Context | Learning disabilities and behaviour that challenges: service design and delivery | Guidance [online] Available at: <https://www.nice.org.uk/guidance/ng93/chapter/Context>.

⁴ Public Health England (2016). Learning Disabilities Observatory. People with learning disabilities in England 2015: Main report.

⁵ Autism UK (2020). Neurodiversity. [online] Available at: <https://autisticuk.org/neurodiversity/> [Accessed Dec. 2021].



Some common challenges experienced by autistic people include:

- Social communication and social interaction (including verbal and non-verbal communications; navigating the social world)
- Repetitive and restrictive behaviour (coping with unpredictability and change)
- Over or under-sensitivity to sensory stimuli (reaction to sound, touch, taste, etc.)
- Highly focussed interests or hobbies (may lead to neglect of other aspects of the person's life)
- Extreme anxiety (particularly in social situations or when facing change)
- Meltdowns and shutdowns (can be very intense and exhausting for the person)¹



Some unique talents and skills that autistic people have include (but not limited to);

- Having logical and methodical approaches
- Good problem-solving skills
- Punctuality and reliability
- Exceptional attention to detail
- Creative thinking
- Strong technical skills (e.g., in IT) with some exceptionally talented and gifted

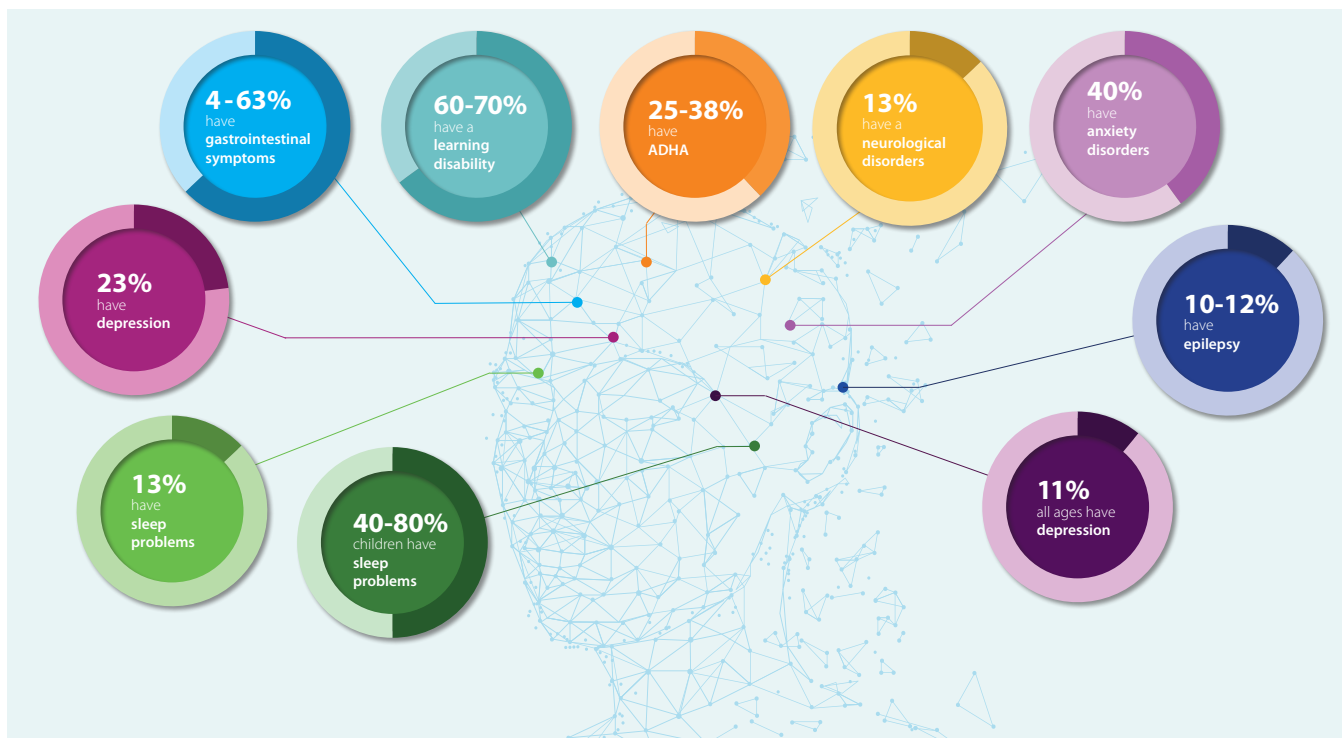
The causes of autism are unknown. It is common for signs of autism to present themselves from a young age. Needs led rather than diagnosis dependent support, with a recognition of neurodiversity is vital. Reading strongly advocates for the importance of neurodiversity, describing autism **as a difference and not a deficit**, seeking to maximise the opportunities for neurodivergent children and young people.^{6,7}

⁶ Brighter Futures for Children (2021). A growth approach to autism. [online] Brighter Futures for Children. Available at: <https://brighterfuturesforchildren.org/professionals/school-standards-services/school-standards-service-a-growth-approach-to-autism>

2.1 Co-occurring conditions

Autistic people often have co-occurring conditions, including dyslexia, dyspraxia, epilepsy, depression, anxiety, ADHD and behaviours such as difficulty sleeping and self-harm. The frequency of co-occurring conditions, means autism is less likely to be diagnosed, leading to inequalities in access to health services and care.⁸ Recent studies have shown that approximately 70% of autistic people also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that has an impact on daily life. A learning disability occurs in approximately 50% of young autistic people.⁸

Figure 1: Co-occurring conditions



Caring and supporting an autistic person can be demanding but also rewarding. Demands on families providing ongoing care and support without breaks can be significant. Societal attitudes to autism and the level of support provided by local and national authorities are important factors determining the quality of life of autistic people.

Support needs

Some autistic people can live independent lives, but others may face additional challenges and require extra care and support. Amongst those that do, the type and level of support needed will vary considerably. Some autistic people need full time care, others will benefit from a small amount of support to help with certain activities or situations. Support aims to enable autistic people to live their lives in the way they choose.⁹ Although a diagnosis of autism is not always necessary to access groups and some services, for many people, being diagnosed with autism helps to ensure they are able to receive the right support, including adjustments at work or school, and helps them to make sense of their experiences and some of the challenges they face.¹⁰ This strategy aims to ensure actions are implemented that will benefit all autistic people in Reading whether they have a diagnosis or not.

⁷ NICE (2011). Context | Autism spectrum disorder in under 19s: recognition, referral and diagnosis | Guidance | NICE. [online] www.nice.org.uk. Available at: <https://www.nice.org.uk/guidance/cg128/chapter/Context>.

⁸ WHO (2017). Autism Spectrum Disorders. Available at: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>.

⁹ National Autistic Society. Available at: [Varying support needs \(autism.org.uk\)](https://www.autism.org.uk)

¹⁰ National Autistic Society. Available at: [Adults \(autism.org.uk\)](https://www.autism.org.uk)

3.0 Why a Reading Autism Strategy is needed

The National Strategy for autistic children, young people and adults, 2021¹¹ places a statutory duty on local authorities working in partnership with the NHS, the voluntary sector, and autistic people to implement actions in relation to the provision of services for autistic people.

Our strategy will align with the commitments in relevant best practice guidance and other national policies, including the NHS Long Term Plan 2019 which pledges to:

“do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.”¹²

The Autism Act (2009) highlights the need for the development and regular review of an autism strategy to make provision to meet the needs of autistic adults. Autistic people, their families, carers and professionals that support them, have told us they experience many barriers in meeting their needs. This strategy is a plan that clearly states the goals, priorities and actions to be taken. A better understanding, acceptance and culture shift in Reading will help address many of these barriers. This strategy will be for 4 years from 2022 – 2026. The strategy actions will need to be embedded in organisations including the wider community to ensure its sustainability, and ability to develop as needs change.

Autism inequalities and barriers to support

Despite autism being a national priority, autistic people are disproportionately affected in various areas. Compared to non-autistic people, common inequalities experienced by autistic people include reduced access to public services and spaces, a gap in employment opportunities^{13,14}, poorer health outcomes, increased likelihood to report a lower quality of life¹⁵ and social isolation, which also impacts health^{16,17}. Action to prevent further widening these gaps is vital.

Autistic people are more likely to die early from factors like suicide, cardiovascular disease and mental health problems. Suicide is a leading cause of early death for autistic people with autistic adults with no additional learning disability being over 9 times more likely to commit suicide than the general population and autistic children experiencing suicidal thoughts 28 times more compared to children in the general population^{17b, 17c}. It is more likely for autistic people to require hospital care or use emergency services than non-autistic people. Many children are diagnosed late; especially girls, resulting in a gender gap, with higher prevalence reported in males than females (ratio of 3:1). Racial, ethnic, and socioeconomic disparities associated with autism also exist.

The Covid-19 pandemic and its effects

Existing challenges experienced by autistic people have been exacerbated by the COVID pandemic such as worsening of mental health conditions, avoidable inpatient admissions, loneliness and barriers to accessing public spaces. The employment and training market was also disrupted. There continues to be insufficient knowledge of how to make reasonable adjustments to existing services, poor access to mainstream services, alongside limited day opportunities, challenges experienced by families

¹¹ 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] GOV. UK. Available at: <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>.

¹² NHS (2019a). NHS Long Term Plan. [online] Available at: <https://www.longtermplan.nhs.uk/online-version/>.

¹³ Office for National Statistics (2021). Outcomes for disabled people in the UK - Office for National Statistics. [online] www.ons.gov.uk. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020>.

¹⁴ Allen M & Coney K (2018). What Happens Next? 2018: A report on the first destinations of 2016 disabled graduates. The Association of Graduate Careers Advisory Services.

¹⁵ Mason D, et al. (2018) Predictors of Quality of Life for Autistic Adults. *Autism Res* 11(8), 1138-1147.

¹⁶ Ryzewska, E, et al. (2019) General health of adults with autism spectrum disorders – A whole country population cross-sectional study. *Research in Autism Spectrum Disorders* 60, 59-66.

¹⁷ Westminster Commission on Autism (2016). *A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people*.

^{17b} Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5)

^{17c} Mayes, S.D. et al. (2013). Suicide ideation and attempts in children with autism. *Research in Autism Spectrum Disorders*.

and carers particularly seldom heard groups and challenges within education settings. However, the pandemic also led to increased awareness and understanding of challenges experienced in people's lives, in particular, autistic people and their families, evidenced by the Left Stranded report¹⁸ and other research findings. Knowledge and awareness of autism, the needs of the local population, and insights by autistic people and their families, need to be the basis of commissioning decisions.

Although autism diagnosis rates for adults have improved, waiting times for assessment continue to be very long for many, worse than previous years and exceeding the 13-week NICE recommended timescale. Factors that exacerbate long waiting times, include growing waiting lists linked to increasing autism public awareness leading to increased referrals, so, increasing demand on services. This has been heightened by the pandemic, stopping or slowing down some local assessment processes. Longer waits can also be a result of delays in diagnostic pathways resulting from workforce pressures. Despite many challenges in Reading, service development accelerated in terms of digital solutions (provided by Berkshire Healthcare and external providers). The service adapted well, and staff quickly embraced new ways of working and became skilled in online delivery and making greater use of technology. A costed proposal to reduce waiting times to a sustainable 12 months was taken through CCG and BHFT governance and an additional investment of £800K in 21/22 was provided to reduce waiting times and this was increased to £1.6M FYE for 22/23. The new investment is enabling a significant service expansion across the Autism Assessment Team (AAT) and the ADHD Team. The investment is being used both to increase the workforce and to use partnership working with external providers to increase the service capacity which will significantly increase the number of appointments the service is able to offer.

In Reading, we sought insights and feedback from people with lived experience including autistic people, families, carers, voluntary sector organisations and professionals supporting autistic people. They were engaged in relation to topics that covered diagnosis, health, family/carer support, social experience, transport, local services, education, work, training and housing. This supported us to identify needs and better understand where change is required and has shaped our understanding of the issues autistic people and their families face across their lives. These insights have help shaped Reading's Autism Strategy. This strategy and its implementation plans will aim to join up all relevant Reading partners to work collaboratively to break down barriers, tackle inequalities autistic people face and implement the changes we want and need to ensure better outcomes for autistic people.



¹⁸ National Autistic Society (2020a). Left stranded: The impact of coronavirus on autistic people and their families in the UK. [online] Available at: <https://pearsfoundation.org.uk/wp-content/uploads/Left-Stranded-Report-Autism-Covid-2020.pdf> [Accessed Jan. 2021].

3.1 Our Local Plans and Strategies

There are three key strategies for Reading which already include the needs of autistic children, young people and adults and they people who care for them. These are explained below:



The Berkshire West Health and Wellbeing Strategy 2021-2030 has been adopted which sets out how local authorities, the Clinical Commissioning Group and partners will work together to support local people to live healthier and happier lives. The jointly agreed five priorities are:

1. Reduce the differences in health between different groups of people.
2. Support individuals at high risk of bad health outcomes to live healthy lives.
3. Help children and families in early years.
4. Promote good mental health and wellbeing for all children and young people.
5. Promote good mental health and wellbeing for all adults.

Autistic people are recognised in this strategy as being one of the groups at risk of having poorer health, including poorer mental health.



Reading Borough Council's 2021 Corporate Plan is built around three themes:

- Healthy environment
- Thriving communities
- Inclusive economy

Autistic people and their families will benefit from local commitments to make Reading a town which supports health and healthy choices, made up of communities which celebrate diversity and are aware of, understand and accept everyone, and plans to improve access to education, training and work which enhances wellbeing.

¹⁸ National Autistic Society (2020a). Left stranded: The impact of coronavirus on autistic people and their families in the UK. [online] Available at: <https://pearsfoundation.org.uk/wp-content/uploads/Left-Stranded-Report-Autism-Covid-2020.pdf> [Accessed Jan. 2021].



Brighter Futures for Children (BFFC)¹⁹ leads on Reading's Special Educational Needs and Disabilities (SEND) Strategy 2022-27, delivered through seven strands:

- Strand 1: Improving communication
- Strand 2: Early intervention through to specialist provision
- Strand 3: Consistent approaches to emotional wellbeing
- Strand 4: Preparing for adulthood
- Strand 5: Support for families / short breaks
- Strand 6: Capital and School Places
- Strand 7: Funding and finance

The strategy aims to make SEND, including autism, everybody's business by embedding it in the practice of those that work with children, young people and families. The aspiration is to improve outcomes for children and young people by focusing on working together to deliver support in the right place at the right time, foster independence, and ensure their emotional, social and physical health needs are met. Additionally, to have access to universal and specialist services "to lead rich and fulfilling lives and flourish in a healthy, thriving and inclusive borough"

The Growth Approach to Autism in Reading ⁶

Reading is adopting a growth approach to autism because the number of autistic children and young people is growing and both children and their families tell us that their experiences in education, and with other public services, still need to be improved. As in the Growth Approach to Autism in Reading, the shared view of autism is that:

Autism should be a difference not a deficit. We advocate for the importance of neurodiversity in our society because diversity gives strength to an organisation, to our communities, and the world we live in. Diversity results in better performance, quality of working environment, and life. Neurodiversity is important to understand and support because children and young people who are not neuro-typical have a lot to contribute and it is our job to make sure they get the opportunity to do so. This is not only because it makes their world better but because it makes our world better.

¹⁹ BFFC are a company limited by guarantee, wholly owned by Reading Borough Council, but run by an independent Board of Directors.

4.0 National Prevalence

Autism prevalence in the UK population aged 5 years+ is 1.1%^{20,21}, equating to about 700,000 children and adults. If families and carers are included, autism is part of daily life for 3.7 million people¹. Autism was once considered to be an uncommon developmental disorder but recent studies have reported increased prevalence.⁷ Autism prevalence was found to be higher in men (2%) than women (0.3%) [likely lower than it should be due to females masking and underdiagnosis].

Several recent studies, along with anecdotal evidence, have come up with varying male/female ratios. Whatever the true ratio, clinical referrals to a specialist diagnostic centre have been reported to see a steady increase in the number of females referred. Due to the male gender bias, females are less likely to be identified as autistic. Many females are never referred for diagnosis and may be missed from the statistics. There is a growing consensus amongst practitioners and academics that the real figures for male/female ratios are broadly equal and as we learn more about how autism presents in females and clinical understanding is updated, we will see increased and earlier diagnoses. Having a diagnosis can be the starting point in providing appropriate support for autistic girls and women, including accessing a community of peers. Prevalence estimates are summarised by gender below.

Table 1: Summary of estimated National Autism prevalence

Population Group	Estimated Autism Prevalence
Adult males	2%
Adult females	0.3%
Adult males - no learning disability	1.8%
Adult females - no learning disability	0.2%
Adult males - with a learning disability	36.3%
Adult females - with a learning disability	29.9%
Boys	1.9%
Girls	0.4%
Children with special educational needs	13.9%
Children with no special educational needs	0.1%

Estimating the Prevalence of Autism Spectrum Conditions in Adults/Mental Health of Children and Young People, 2017²⁰

²⁰ NHS Digital (2018). Mental Health of Children and Young People in England, 2017 [PAS]. Autism spectrum, eating and other less common disorders. - NHS Digital [online]. Available at: MHCYP 2017 Less Common Disorders.pdf (digital.nhs.uk)

²¹ NHS Digital (2012). Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey>.

5.0 Local Context

5.1 How the strategy was shaped

Development has been supported by a range of key stakeholders, including autistic people and their families and carers, third sector and voluntary organisations and professionals from across the Reading system (see Introduction, page 4). Engagement and coproduction (though limited in its scope by resources) took place via a mixture of interviews, workshops, surveys, forums, existing local groups, and feedback sessions. This insight was used to inform and shape the strategy, and to test emerging findings, recommendations, priorities, and vision development. We are extremely thankful to all contributors and partners, expressly to autistic people, families and carers who helped shape this strategy, welcomed us to their groups, responded to our surveys and attended workshops. This strategy was developed through two phases from November 2021 to May 2022.

Phase 1: defining the current state and needs

- Reviewing strategic documents, current level of provision and support
- Determining population health need
- Stakeholder engagement and consultation
- Development of an Autism Needs Assessment

The main aim for this phase was to understand the existing challenges and identify potential future opportunities for improvement to inform the development of the strategy.

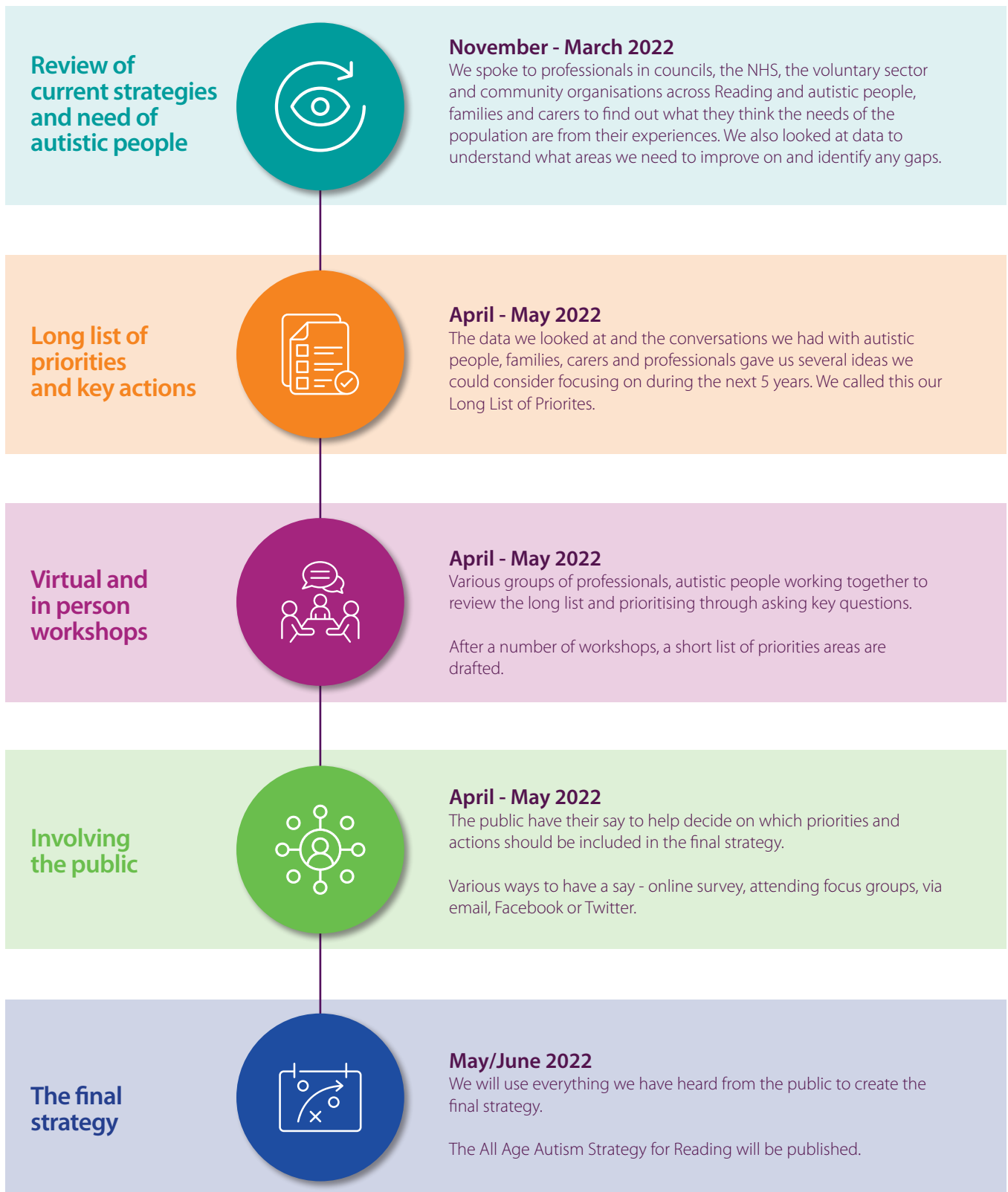
Phase 2: Prioritisation, vision and strategy development

- Co-development of a local vision and key aspirations and production of a long list of priorities and action areas. Prioritisation process: criteria to review the priorities against to produce a shorter list e.g., for focus in the first year/few years of strategy.
- Strategy development and testing with autistic people, their families, and those who support them to ensure the strategy and focus reflected identified needs, was fit for purpose and adequately ambitious.

Phase 3: Delivery

Upon deciding how the strategy will be taken forward to ensure the best approach for best outcomes for Reading's population, the next phase of delivery will begin.

Figure 2: The Autism Strategy Development Process



5.2 Our Ambitions



To continue working across the system to achieve a culture shift moving towards needs-led rather than diagnosis dependent support and with a recognition of neurodiversity:

- Accessing help based on need, as early as possible, promoting acceptance of neurodiversity, strength-based approaches, and shared language.

Doing WITH rather than doing TO and enabling and celebrating strengths while fostering independence.

Strengthening understanding, recognition, and support to make life better for autistic people.

For autistic people to be proud, independent and be able to give back to society

6.0 Priorities

This All-Age Autism Strategy for Reading and identified priority areas have been informed by the All-Age Autism Needs Assessment and what autistic people and their families, carers and those working with autistic people have told us.

1. Improving awareness, understanding and acceptance of autism within society
2. Improving support and access to early years, education and supporting positive transitions and preparing for adulthood
3. Supporting more autistic people into vocational training and employment
4. Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care
5. Housing and independent living
6. Keeping safe and improving support within the criminal and youth justice system
7. Improving support for families and carers

Priority 1

Improving awareness, understanding and acceptance of autism within society

Aligns with Reading's SEND Strategy :

Strand 1: Improving communication



Our Ambition

An understanding and supportive society to empower autistic children, young people and adults to live fulfilling lives while fostering culture change towards acceptance of difference which reduces barriers.

What we know nationally

The national autism strategy puts emphasis on working towards meaningfully improving public understanding and acceptance of autism, and ensuring autistic people feel less isolated/lonely and feel more included in their communities. The long-term goal is for more public sector services, businesses, and organisations to be more autism inclusive.

What we know in Reading

Ensuring that autistic people can enjoy fulfilling lives in Reading depends on improving awareness, understanding and acceptance across a wide range of services and within the local area as a whole. Children's centres, schools, youth services, GPs and other health services, and voluntary and community organisations and activities – all play their part in helping families to identify the signs of autism and access diagnosis, and with developing strategies to support autistic people and ensuring that they can access support and opportunities. Universal services also play a key role for autistic adults. Emergency services, transport providers, health services such as hospitals, leisure services and other statutory services like the Job Centre must make reasonable adjustments to ensure that autistic people can access and benefit from their services.

Within Reading's Brighter Futures for Children's Autism Advisory Service, families that receive a diagnosis of Autism for their child are supported. The Autism Advisor works with various staff and organisations to raise awareness, understanding and support autistic people and their families.

Training uptake is monitored and recorded. Specific training is provided to staff who carry out statutory assessments on how to make adjustments in their approach and communication for autistic people.

This training is available to staff in Adult Social Care, Children and Young People's Social Care, the Child and Adolescent Mental Health Service (CAMHS), and the NHS Neurodisability Team. Training and awareness delivery can take place through Family Involvements, Seminars, Staff Consultations, Home Visits, Virtual Visits and Parent Training through the Living with Autism 6-week course.

Autism training in schools varies depending on each individual school. The Reading Autism Education Trust (AET) training hub has been recently established which all schools can now access. This will ensure all schools have access to the same training to ensure consistency across Reading. Schools will be asked to embed the AET standards & competencies to help ensure a cultural of change is encourage.

Royal Berkshire Hospital has been accepted by National Autistic Society as a pilot site for Oliver McGowan Mandatory training. A training programme of Positive Behavioural Support for people with learning disability and or autism and behaviour that

Priority 1

Improving awareness, understanding and acceptance of autism within society

challenges is being rolled out to key staff in health, social care, education, support providers, the voluntary sector and family carers during 21/22.

Although various training has been developed and delivered, there is a need to address gaps and for a comprehensive multi-agency autism training plan, raising awareness and facilitating access especially for seldom heard autistic groups.

What is important to Reading people

Through our engagement with autistic people, parent carers and supporting services and professionals across Reading, key areas highlighted included:

Education

- Behaviour within schools can be misunderstood resulting in inappropriate disciplinary action.
- Training is needed for both teachers and other children on autism.
- Build upon existing training resources such as Autism Education Trust (AET)
- Differing interpretations of meeting need, understanding of autism, is still low

Social Experience

- Bullying and exclusion from social events is a common significant problem for autistic children.
- There needs to be more inclusion and training for sports clubs
- Better awareness of what autism is and environmental/sensory impact on autistic people

Employment

- Better understanding, awareness, and acceptance of autism by employers and guidelines around autism would be beneficial
- Reasonable adjustments for autistic employees need to be improved
- There can be a lack of support or employment assistance those over 25 years
- There needs to be self-esteem building to get into the workplace

Pre and Post Diagnosis Support

- Need for ongoing improved understanding and awareness of autism within the Education sector (building on the AET training available to schools)
- Some parents find it easier to advocate for their children than others.
- There needs to be more general awareness, to help break social isolation
- Some people felt that post diagnosis support is not clear and there is limited information between referral and assessment for autism.

Transport

- Training for transport staff, and better awareness of autism is key to improving services
- Autism awareness has gone up significantly, but resources have gone down significantly.
- Support to navigate information, advice and guidance on a wide range of topics
- Many autistic people are not aware of the services available to them.
- Positive feedback received for local services provided by the VCS

Priority 1

Improving awareness, understanding and acceptance of autism within society

Training

- Autism awareness raising sessions to support autistic people for: healthcare and education professionals, businesses, employers, statutory professions
- Training for social care teams about parent carer needs assessments, disability legislation and clear pathways to support parents experiencing aggression or destructive behaviour from their autistic child. Families want their concerns and the impact it has on them acknowledged, honesty, and a clear system in place to support them, drawing on best practice.
- All professionals to ensure families have the SEND guide and know about the Local Offer and parent carer needs assessments
- Criteria for Community Team for People with Learning Disabilities (CTPLD) and children's social care are updated and publicised with parents and professionals.

More training/awareness raising/refresher courses would be welcomed, with an acknowledgement that hands on experience and learning to see autistic people as "individuals and not a series of conditions" are key. Training is often much more effective when delivered/co-delivered by experts by experience.



Priority 1

Improving awareness, understanding and acceptance of autism within society



What we aim to do as a partnership

We will:

- Expand the Autism Board to improve representation (autistic adults, with lived experience of being diagnosed with autism and from diverse backgrounds, work and training providers, criminal justice diversion services, and more voluntary sector partners).
- Create opportunities for more regular and informal engagement (coffee mornings, autism forums)
- Review pathways to ensure these recognise specific needs of older autistic adults, women with autism, autistic people from ethnically diverse backgrounds.

Awareness and Training

We will:

- Develop a comprehensive multiagency training plan to ensure more public sector services, businesses, and organisations, including the private sector, become more autism inclusive within Reading and for all to be aware of safeguarding, a trauma informed approach and have a person-centred approach and understanding of need (including for staff in courts and probation services involving registered intermediaries where relevant).
- Address Employment by improving understanding and guidelines for employers, including reasonable adjustments (applying anticipatory reasonable adjustments duty - Equality Act 2010)
- Improve public understanding of autism and inclusion across Reading Borough Council and Brighter Futures for Children.
- Develop and test autism public understanding and acceptance initiative, working with autistic people, their families and the voluntary sector.
- Use multiple methods of raising awareness of existing pre and post diagnostic support provision and making it clear and easy to find, including addressing language and cultural barriers for underrepresented groups, to aid proactive identification of people awaiting assessment, crisis prevention and prevention of avoidable admissions into inpatient mental health settings, making it easier to find and engage with the appropriate support, offered throughout the life course.

Priority 2

Improving support and access to early years, education and supporting positive transitions and preparing for adulthood

Aligns with Reading's SEND Strategy

Strand 4: Preparing for adulthood &

Strand 6: Capital and School Places



Our Ambition

Schools, staff, students to have a good understanding, awareness and respect of autism and for all autistic people to have equal access to life chances.

What we know nationally

- 6 in 10 young people, and 7 in 10 parents, say that the main thing that would make school better for them is having a teacher who understands autism.
- Fewer than 5 in 10 teachers said they are confident about supporting an autistic child.
- Autistic children are twice as likely to be excluded from school.

What we know in Reading

- Many autistic young people have reported being bullied and/or isolated from their peers and struggling for schools and colleges to take this seriously. Many have reported anxiety preventing them from attending school or attending full-time.
- A joint inspection of Reading by Ofsted and the Care Quality Commission judged Reading's SEND local offer to be amongst the strengths of the partnership, identifying that families had widespread awareness of the online resource and that the local offer team were effective in following up contacts to ensure needs were met. The Local Offer team have also won a national award.
- About 2% of children in mainstream primary and secondary schools in Reading have had autism identified as a primary need, compared to a national rate of 1.44%. The average number of autistic children attending non-selective secondary schools in Reading is 19, with up to 30 attending the largest schools, and 7 autistic children attending each primary school in Reading, including up to 14 children in the largest primary schools. This proportion has increased over the last five years. Some local experts believe that schools with a good reputation for supporting autistic children may be more attractive to families, so a higher number of autistic pupils than average may attend those schools.
- Most autistic children are educated in mainstream schools. Numbers of autistic children in mainstream schools has increased over the last five years and are expected to continue to increase. Although this in part reflects that the total number of pupils in schools has also increased, autism prevalence in the under 25 population in Reading also increased from around 7 per 1,000 in 2017 to 9 per 1,000 in 2020
- Numbers of Reading EHCPs where autism is recorded as the primary need have increased and have consistently represented around 35% of all EHCPs each year; slightly higher than nationally (27% of children with EHCPs in 2017). 2,725 EHCPs were funded between 2017 and 2022. Reading has a higher rate of EHCPs than the national average and its statistical neighbours.
- Percentage of all children in Reading who received a permanent exclusion fell from 0.153% in 2016/17 to 0.06% in 2019/20 (15 exclusions in a school year), now in line with national averages and Reading's statistical neighbours (higher than the South-east average).

Priority 2

Improving support and access to early years, education and supporting positive transitions and preparing for adulthood

- There are currently 402 places at Reading schools with special provision. These include 301 places in dedicated special schools. Some schools support autistic children well, but this is not consistent across schools.

What is important to Reading people

Education and School life

- Ongoing improved understanding and awareness of autism within the education (building on the AET training available to schools) including applying a trauma informed approach to support.
- Some schools support autistic children well, but this is not consistent across schools.
- Insufficient support and signposting after completing school or to enter into employment
- Bullying within schools is common and can result in autistic children missing school

‘I’m of the generation where ADHD/ASD wasn’t a thing – It was just naughty children, so I never got any help, and ‘depressing - I didn’t enjoy it, I was always being bullied’.

‘My school never recognised my issues and dismissed me when I was struggling. I was told to ‘stop being anxious’ constantly.’

‘My experiences at school will always have an impact on me throughout my life.’

Several autistic people shared similar experiences of “bullying” and being “pulled out of school” due to mental health, “pressure of school as well as how they were treated by some of their teachers”. Instead of being offered to “tell what you can do”, they were “always told instead what they cannot do”, ‘making finding a job harder’.

Professionals expressed that “early identification and support of Education and Health Care Plan (EHCP) in place before entry to school would support children to thrive”.

- Statutory services such as “teachers, social services, medics, counsellors, the police” and Employers... “all need to learn about autism without intellectual disability”
- “Mental health support needs urgent attention” for autistic people.
- “More financial support for disabled autistic people”
- Parent carers reported ‘access to special needs school can be improved’ and ‘need universally accessible public services (starting with a suitable education for my child), and professionals who discharge their statutory duties according to the law.



Priority 2B

Supporting Transition and Preparation for Adulthood

Aligns with Reading's SEND Strategy -

Strand 4: Preparing for adulthood &

Strand 6: Capital and School Places

What we know nationally

Guidance and best practice

NICE guidance on transition from children's to adult services covers the period before, during and after a young person moves from children's to adults' health or social care services, and how this transition should be managed and services work together to support a good transition. The guidance recommends that transitions should take place not by a rigid age threshold, but at a time of relative stability for the young person. This is also supported by the NHS Long Term Plan that commits to offering person centred and age-appropriate care for health needs, rather than basing transitions solely upon age.

Supporting smooth transition to adult services for young people going through the diagnostic pathway and ensuring data collection and audit of the pathway takes place (CG128)⁷ is a key guideline.

Transition to adult services (dependent on individual need)

- Provide information about adult services to the young person and their parents/carers, including their right to a social care assessment at 18 years of age
- Involve the young person in discussing and planning
- Train staff in autism awareness and skills in managing autism including the importance of key transition points, such as changing schools or health or social care services
- For those who are 16 years and older with complex and severe needs, a care programme approach (CPA) is recommended as an aid to transfer between services

Priority 2B

Supporting Transition and Preparation for Adulthood

What we know in Reading

Moving on to further education, training or work is an important time for autistic young people. While there are several options available in Reading, person-centred support is important to help autistic young people to find the right opportunity. More internships, apprenticeships and meaningful work experience for young people would enhance prospects for autistic people. Within Reading, Children's Transitions to Adult Social Care services is outlined in the Preparing for Adulthood Policy (2019) which aims to ensure that young people and adults have appropriate support as they move into adulthood, and there are no gaps in the delivery of services. The strategy complements the Preparing for Adult Pathway. The Preparing for Adulthood Panel has responsibility for co-ordinating identification and monitoring of the children and young people who may or will require services as they transition into adulthood. Reading Mencap provide the Preparing for Adulthood service funded by Reading Borough Council that support young people and adults (16-25) and their families in preparing for adulthood. A Transitions Family Adviser offers an independent, outreach, information, advice and support service to guide young people and their families through the complexities of becoming an adult, to manage the changes in social care, benefits, housing, health, education, employment and financial management.

As of February 2022:

37%

of young people open to Preparing for Adulthood (PFA) have a **primary or secondary diagnosis of Autism**

33%

of young people open to Preparing for Adulthood (PFA) have a **diagnosis of a learning disability and Autism**

Youth Offending Service (YOS)

Young people transitioning from YOS will involve Adult Probation Services from age 17. Dependent on needs, the transfer may occur at age 18 but could be later.

Healthcare transitions

Within Berkshire Healthcare Children, Young People and Family Services, for young people with long term health conditions, transitions should begin at the age of 14, with the transition usually occurring between the ages of 16 and 19. The child or young person and their families should receive the following to support with their transition to adult care services²³:

- A named transition co-ordinator
- Received information on the adult service(s) they're transitioning to
- Completed a transition health care plan and received a discharge summary.

²³ Berkshire Healthcare NHS Foundation Trust (2022). Transition to Adult Services | Children Young People and Families Online Resource. Children Young People and Families Online Resource. Available at: <https://www.berkshirehealthcare.nhs.uk/5940>.

Priority 2B

Supporting Transition and Preparation for Adulthood



What we aim to do as a partnership

Culture change

We will:

- Tackle bullying within schools, and inappropriate exclusions.
- As well as awareness raising in schools, we will implement additional measures to including zero tolerance policies for bullying, autistic champions in schools, and regular whole school and class discussions.
- Increase Autism support in schools including access to support from Occupational Therapist/Speech and language therapists
- Ensure schools are reminded of the support available that they share with parents (resources shared to use inclusive language)
- Ensure person-centred support is in place to help autistic young people to find the right opportunity.

Transitions & Diagnosis

We will:

- Strongly encourage schools to share information they receive about local support and activities – need to ensure this information is shared with all children/families with additional needs.
- Ensure school transport is appropriate for autistic children through training for drivers and escorts to know the needs of the autistic children and how best to communicate with them, to provide better assistance. We will liaise with relevant Transport teams to achieve this.
- Support autistic children and young people to ensure better outcomes throughout their education by schools making reasonable adjustments and a commitment to address bullying towards autistic children.
- Increase support and signposting after completing school e.g., to enter employment (more choice, employment opportunities, work experience etc).
- Put in place effective planning for adulthood including social care after turning 18 and when finishing school/college if later.
- Improve transitions planning for all (education/social care/health) children and adult services – more work needs to be done so Young People and family are provided with robust information to support.
- Support people into adulthood through volunteering opportunities
- Create additional internships, apprenticeships and meaningful work experience for young people which enhance prospects for autistic people.
- Support smooth transition to adult services for young people
- Ensure data collection and audit of the diagnosis pathway takes place

Priority 3

Supporting more autistic people into vocational training and employment

Aligns with the Joint Health & Wellbeing Strategy:

Priority 1: Reduce the differences in health between different groups of people



Our Ambition

Through understanding, awareness and acceptance of autism, autistic people can become integrated as part of society and gain employment and confidence. Including maximising life chances and opportunities and empowering autistic people to meet their potential.

What we know nationally

Training and Employment

- The National Autism Strategy, Equality Act 2010, Care Act 2014, Care and Families Act 2014 and the NHS Long Term Plan 2019 emphasise the importance of facilitating access to education, training and employment opportunities and sustained support, including skills development to empower people to independence wherever possible.
- Approximately 10-15% of autistic adults nationally are in full-time employment and overall, 22% of autistic adults (16-64 years) are in employment (any form).
- Disabled people with autism (21.7%) were among those disabled people with the lowest employment rate and compared to 81% of non-disabled people, showing a significant employment gap for autistic people.

What we know in Reading

- Barriers for autistic adults wanting to be in employment include absence of effective transition from education; absence of reasonable adjustments at interview and in workplaces; unsuitable HR practices and recruitment methods; lack of employer awareness and difficulties accessing support to get into work or when in work.
- Positive changes are recognised in improved access to services, but further work is required.
- There are limited employment support options available for people over 25 years
- The gap between training and employment support needs bridging
- Remove the current cliff edge when young people enter employment after 18+
- Support provision for late diagnosis for people already in employment is needed
- Employers need organisations to go to for support and training

What is important to Reading people

Training and Employment

- Many autistic people want to work, are able to and would value support and awareness of pathways and available opportunities for employment.
- Improved understanding, acceptance, and guidelines for employers around autism, including reasonable adjustments and support for autistic young people to enter the workplace
- Improved support and employment assistance for those over 25.

²³ Berkshire Healthcare NHS Foundation Trust (2022). Transition to Adult Services | Children Young People and Families Online Resource. Children Young People and Families Online Resource. Available at: <https://www.berkshirehealthcare.nhs.uk/5940>.

Priority 3

Supporting more autistic people into vocational training and employment



What we aim to do as a partnership

Work, volunteering and training

We will:

- Increase volunteering opportunities
- Identify the strengths and needs of neurodivergent children and young people and adults and support them to make good progress and have good outcomes
- Improve options for young people to increase current opportunities
- Develop a clear pathway through school, from school, in further and higher education and into vocational training and work opportunities
- Further develop and promote Elevate Project for autistic young adults
- We will enable and address specific needs of autistic adults through Reading's Economic Covid Recovery Plan
- Establish peer mentorship/championship training
- Increase understanding of barriers faced with the benefits system and support to overcome these
- Support autistic people to get into employment and offer support during employment
- Work with partners and local employers to increase employment opportunities and job support for all autistic adults of working age
- Improve understanding and guidelines for employers, including reasonable adjustments both during recruitment and in employment.
- Improve support and employment assistance for those over 25
- Support autistic young people to enter the workplace
- Organisational members of the Autism Board will seek and promote their recognition as employers of people with disabilities, leading by example when approaching commercial/ industry partners

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Aligns with the Joint Health & Wellbeing Strategy:

Priority 1: Reduce the differences in health between different groups of people

Priority 2: Support individuals at high risk of bad health outcomes to live healthy lives.

Priority 3: Help children and families in early years.

Priority 4: Promote good mental health and wellbeing for all children and young people.

Priority 5: Promote good mental health and wellbeing for all adults.

Aligns with Reading's SEND Strategy:

Strand 2: Early intervention through to specialist provision

Strand 3: Consistent approaches to emotional wellbeing



Our Ambition

Strengthening understanding, recognition, and support to tackle health inequalities experienced by autistic people and to make life and health outcomes better for them. We will continue working across the system to achieve a culture shift moving towards needs-led rather than diagnosis dependent support and with a recognition of neurodiversity. We will have demonstrated improvements in reducing assessment and diagnosis times and support to ensure help is accessed based on need, as early as possible, promoting acceptance of neurodiversity, strength-based approaches, and shared language.

What we know nationally

Autism inequalities and barriers to support

- Inequalities experienced by autistic people include reduced access to public services and spaces, the gap in employment opportunities, poorer health outcomes, increased likelihood to report lower quality of life and social isolation.
- Contributory factors to inequalities in health include challenging communication in inaccessible environments, reduced likelihood to understand signs of poor-health, barriers to NHS service access when needed, uncertainty which brings on anxiety, sensory variances, different responses to pain and difficulty identifying own emotions.
- Early identification, improvements in diagnostic pathways for all ages and reductions in assessment waiting times are key to timely diagnosis and appropriate access to support. This enables autistic people and those supporting them to better understand their needs.
- Many children are diagnosed late; girls are particularly affected as signs of autism are frequently not recognised, resulting in delays in diagnosis until adolescence or adulthood.
- While the diagnosis of adult autism has improved over the years, in Reading adults have to wait years for a diagnosis rather than the National Institute for Health and Care Excellence (NICE) recommended 13 weeks between referral and first assessment.
- There is a gender gap in the prevalence of autism, with higher prevalence reported in males than females which may result from underdiagnosis of autism in females.
- Autistic people have a lower life expectancy (16-year gap) and are more likely to require hospital care or use emergency services than non-autistic people.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- Improving health and care staff's understanding of autism is crucial in enabling progress on reducing health inequalities for autistic people.
- It is suspected that 'detection bias' relating to socioeconomic status means diagnosis may be less likely in children from lower socioeconomic status households and with parents with lower educational attainment levels.
- Racial, ethnic, and socioeconomic disparities associated with autism exist throughout many service areas including access to early assessment, diagnosis, and therapeutic interventions.
- To tackle the health and care inequalities autistic people face, the government passed the Health and Care Act 2022, which included the Oliver McGowan Mandatory Training in Learning Disability and Autism, which will educate and train health and social care staff, at the right level for their role, to provide better health and social care outcomes for people with a learning disability and autistic people.

What we know in Reading

Diagnosis

- In Reading we have implemented a Needs-led, rather than Diagnosis Led approach so that support in schools can be put in place before diagnosis.
- The Berkshire Healthcare NHS Foundation Trust (BHFT) Autism Assessment team based at University of Reading are responsible for diagnosis of children and young people under 17 and a half years. Unfortunately, due to strong demand, the waiting times are over 2 years, well in excess of the 13 weeks NICE guidelines
- Nationally £13 million is being invested in reducing waiting times for all, and Berkshire West CCG has received extra funding to recruit more staff to be able to offer more assessment to children and young people to reduce waiting times for assessment.
- The Neuropsychology ASD Team from BHFT based in Erleigh Road, are responsible for adult diagnosis. Unfortunately, due to strong demand, the waiting times for an adult diagnosis are approximately 4 years, well in excess of the 13 weeks NICE guidelines.
- In Berkshire autism assessment referrals for children and young people, increased from 1209 in 2016/17 to 2045 in 2021/22, a 69% increase. More resources have been commissioned, including a private online provider to reduce waiting times but these have remained stubbornly high.
- For the adults diagnostic pathway, there has been an increase in the number of people referred for a diagnosis but, there has been no increase in resources resulting in increasing waiting times.
- Due to the long waits, Berkshire West CCG commissioned the Pre and Post Autism and ADHD Service for 0 to 25 in 2019. The service was co-produced with partners from health, education and social care plus Reading Families Forum and the voluntary sector. Autism Berkshire, with Parenting Special Children won the tender and started delivery in 2020.
- The new Berkshire West CCG NHS Autism and ADHD Support service has been very successful. In 2021 Autism Berkshire supported over 500 families, with evidenced based graduated support from Helpline calls, one to one consultations, short courses and long courses. The Teen Life course for parents of young people from year 6 to 11 has proved to be particularly popular with parents as previously there was little support aimed at parents of teenagers.
- Half of the families supported by Autism Berkshire are on the waiting list and 40% of the children and young people supported are girls.
- For families of children who receive a diagnosis, support is available from Reading's Brighter Futures for Children Autism Advisor. The service is not available to families on the waiting list.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- The BHFT Autism Assessment Team (AAT) send referral packs providing information on all sources of family support to parents, once a child is added to the waiting list for assessment, to ensure families access this as soon as possible including provision of a letter for school to emphasise need for needs-led support. This includes information about the Berkshire West Autism and ADHD Support Service provided by Autism Berkshire. There are Comprehensive online resource provision with help and advice on a wide range of developmental, emotional/mental health concerns.²⁴
- BHFT AAT also run the SHARoN online support network (Support, Hope and Resources online Network) for parents of children and young people waiting for an assessment, or with a diagnosis. The service is moderated by professionals, including the voluntary sector and available online 24 hours a day to parents.
- BHFT deliver co-produced training courses such as the Psychological Perspectives in Education and Primary care (PPEPcare) which is commissioned by the CCG for delivery to health, education, social care and other agencies which equips settings to provide needs-led support.
- Many parents and adults are frustrated by the long waits and seek a private diagnosis.
- Through the engagement process for this strategy, we found that some parents who were waiting for an assessment or who had received an autism diagnosis for their child, were not aware of the Berkshire West CCG NHS Autism and ADHD Support Service, nor the Local Offer and Family Information Service.

Post Diagnostic support

- The BHFT Autism Assessment Team offer a diagnosis only service.
- Post diagnosis support is available from the Berkshire West CCG NHS Autism and ADHD Support Service provided by Autism Berkshire, a local charity set up in 1990 by families of autistic children and those with challenging behaviour. All staff have lived experience and professional training and qualifications in family support and autism. Research has shown that the most effective support for families is peer led support such as the Autism Berkshire service.
- Currently there is no Positive Behaviour Team to support parents whose autistic children have violent and challenging behaviour. It has been agreed this is a gap in services, and the local NHS commissioners, Berkshire West CCG had run a commissioning process in Spring 2022, but not awarded a contract.
- For adults the Neuropsychology ASD Team from Berkshire Health NHS Foundation Trust runs a post-diagnosis course 'Being Me' to help newly diagnosed adults understand autism and how it impacts their life.
- Reading Mencap run an Information and Advice Service which includes support around health and how to access the Annual Health Check for people aged 14 and older with a Learning Disability and those with Autism and a Learning Disability.
- BHFT run the Community Team for Learning Disability (CTPLD), many adults referred to them have autism as well as a learning disability. The team includes nurses, OTs, Physio, Psychiatrists, Psychologists Dieticians, Speech and language therapists. They work in partnership with social workers to make sure people with a Learning Disability and Autism get the best support possible.

Physical and mental healthcare

- The Royal Berkshire Hospital employs two Learning Disability nurses who are highly trained in autism and are available to anyone who has a Learning Disability or Autism and is visiting the hospital as an outpatient or staying as an inpatient.
- Following feedback from people with a Learning Disability and Autism, and their parents and carers, the Royal Berkshire Hospital implemented a Bleep system to reduce the stress of waiting for outpatient appointments.²⁵

²⁵Your information and what we use it for (royalberkshire.nhs.uk) this should say Use the Bleep

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- The Royal Berkshire Hospital also has a series of Easy Read leaflet for patients with Learning Disability and Autism available on their website.²⁶
- Many of Reading's GP have included details of the Berkshire West Autism and ADHD Support Service on their website under the Wellbeing section.²⁷
- Berkshire West has a Learning Disability Mortality Review, LeDeR Steering Group, which carries out a number of projects, including collating and sharing anonymised information about the deaths of people with learning disabilities, including those with LD and autism so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements, to try to reduce the early mortality of people with a Learning Disability and those with Autism with Learning disability .
- A training programme of Positive Behavioural Support for people with learning disability and or autism and behaviour that challenges is being rolled out to key staff in health, social care, education, support providers, the voluntary sector and family carers during 21/22.
- BHFT is implementing a Neurodiversity strategy to make all BHFT services, everything from health visiting and school nursing to Integrated Pain and Spinal Management and continence service, accessible for people with a learning disability and/ or autism.²⁸

What is important to Reading people

- Better awareness of what autism is and the environmental/sensory impact on autistic people within healthcare settings.
- Waiting times for assessment for children, young people and adults are too long and need to be reduced.
- Waiting times for children and young people who have anxiety and are out of school are too long and need to be reduced.
- Access to appropriate mental health services that understand autism and can make reasonable adjustments need to be improved and a priority.
- Specialist support and pathways needed to address complex health concerns
- Training for hospital staff and GPs about autism, mental health and in responding to autistic adults and children including what other support services are available in the community.
- Having continuity of care from their GP.
- Implementing reasonable adjustments for health appointments including vaccinations is important.

What we will do as a partnership

- Continue to work to reduce waiting times for assessment for children and young people. The project will continue to be monitored by the BHFT board.
- In order to tackle morbidity and preventable death in individuals with autism it is of utmost importance to provide regular physical health checks and to maintain high level of clinical suspicion towards physical health problems in autism.²⁹
- Raise the long waiting times for adult assessments in order to increase resources to bring the waiting times down.
- Raise the lack of a Positive Behaviour Service in order to get the service commissioned.

²⁶ Disabled Patients | Royal Berkshire NHS Foundation Trust contains a list of Easy Read leaflets for LDA patients

²⁷ Autism | Balmore Park Surgery

²⁸ Our Neurodiversity Strategy | Berkshire Healthcare NHS Foundation Trust

²⁹ Sala et al (2020)

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

- All organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West CCG NHS Autism and ADHD support service, as some parents, although sent a referral pack by the AAT, report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- All health and care organisations shall comply with their statutory duty under the Health and Care Act 2022 to ensure that all staff complete their Oliver McGowan Mandatory training in Learning Disability and Autism, so staff feel confident in supporting the individual needs of children, young people and adults with a learning disability and/ or autism.
- We will focus on ensuring there are no barriers to accessing health services for people with a learning disability and/or autism, including access to age 14+ Annual Health Checks for those with autism and Learning Disability. The care they receive will be provided in a suitable environment, by people who understand their needs, with suitable adjustments made when needed for them to receive excellent care.
- Through RBC commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation to prevent help prevent mental ill health in people with learning disability and/or autism

Building the Right Support in the Community and Supporting People in Inpatient Care



Our Ambition

For community support and services to reflect what autistic people and their families say they need.

What we know nationally

Play-based strategies to increase joint attention, engagement and communication including and group based social learning programmes focused on improving social interaction, or individual delivered for people who find groups difficult are encouraged³⁰ Interventions focused on life skills/activities of daily living e.g., leisure activity programme are also recommended.

Transport

- The National Autism Strategy highlights transport as a key enabler in helping autistic people become active members of society, through access to employment, leisure, and community activities.
- Many autistic people favour driving, walking and cycling as alternatives to using public transport which can sometimes be noisy, crowded and an uncomfortable experience.

Inpatient health settings

- Autism prevalence within adult inpatient mental health settings autism prevalence is estimated to be 2.4-9.9%³¹ while autistic people account for 1 in 100 people.

³⁰ <https://www.nice.org.uk/guidance/cg170>

³¹ Tromans S, Chester V, Kiani R, Alexander R, Brugha T. (2018) The Prevalence of Autism Spectrum Disorders in Adult Psychiatric Inpatients: A Systematic Review. Clin Pract Epidemiol Ment Health. 14:177-187.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

What we know in Reading

Support groups

There are groups that support autistic children, young people and adults through social and leisure activities, or by helping autistic people to access education and employment. Some services providing support to autistic people in Reading expressed their experience of some services relying on a crisis response for people of all ages. However, CAMHS, Anxiety and depression as well as the MHSTs, offer counselling and other support for autistic people. Quality support around education, health (mental health) and social care have an important role. They emphasise the need for timely, accessible support.

Transport

- The Reading Transport Strategy 2036 outlines some actions that can be applied to an 'autism-inclusive' approach for this autism strategy.
- Reading Buses have worked closely with local charities such as Autism Berkshire, to implement a driver training course for staff learn about the needs of autistic people.
- BfC offer School Transport contracts to companies that have applied to go on the framework and trained escorts are provided as required.
- Readibus is the specialist service used for School Transport, mostly for wheelchair users but provide 6 buses for the Avenue School – and an ambulance for the most complex needs pupils.
- There are 23 companies in Reading operating routes on the School Transport scheme.
- Around 540 pupils are on the School Transport scheme. Those who are autistic is unknown.

What is important to Reading people

Local (community) services

- Need a range of activities covering the full spectrum including those without significant support needs who live more independently.

Transport

- School transport is not always appropriate for autistic children
- Suggestions on what needs to be done to improve on the experience of using transport services, included:
 - "better cycling integration"
 - "temporary blue badge scheme"
 - "joined up national transport strategy"
 - "additional support of getting driving licence for people with anxiety and sensory difficulties"

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Social Experience

- There is a limited range of activities for autistic children, young people and adults.
- Many of the activities that are for young people are very good but limited and often they reach capacity very quickly e.g., Make Sense Theatre, Chance to dance.
- Young people have expressed they're not interested in competitive activities that require performing - saying they want to spend time with other autistic children.
- Activities like Holiday Clubs are difficult to access due to "not enough support personnel available". Families where both parents are working find the situation "hard".

A gap in provision was identified for autistic adults who have received a late diagnosis "and who have different support needs to those who have grown up knowing why they are different" or who are "without learning disabilities". Local services for autistic adults who have "worked" or "lived independently" are reported "non-existent".



Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care



What we will do as a partnership

Tackling health and care inequalities for autistic people

We will:

- Continue to work to reduce waiting times for assessment for children and young people. The project will continue to be monitored by the Berkshire Health Foundation Trust Board.
- In order to tackle morbidity and preventable death in individuals with autism, we will provide regular physical health checks and to maintain high level of clinical suspicion towards physical health problems in autism.
- Work at addressing issues related to adult assessments in order to bring the waiting times down.
- Work towards addressing the lack of a Positive Behaviour Service in order to get the service commissioned
- All organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West Clinical Commissioning Group NHS Autism and ADHD support service, as some parents, although sent a referral pack by the Autism Assessment Team (AAT), report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- All health and care organisations shall comply with their statutory duty under the Health and Care Act 2022 to ensure that all staff complete their Oliver McGowan Mandatory training in Learning Disability and Autism, so staff feel confident in supporting the individual needs of children, young people and adults with a learning disability and/ or autism.
- Focus on ensuring there are no barriers to accessing health services for people with a learning disability and/or autism, including access to age 14+ Annual Health Checks for those with autism and Learning Disability. The care they receive will be provided in a suitable environment, by people who understand their needs with suitable adjustments made when needed for them to receive excellent care.
- Through RBC commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation to prevent help prevent mental ill health in people with learning disability and/or autism

Building the right support in the community and supporting people in inpatient care

Support groups, services & Training

We will:

- Make available activities (across all ages), increasing social opportunities and social enterprise projects run by local people with lived experience.
- Provide training to adapt holiday clubs to be more inclusive and suit the needs of the autistic person
- Look at funding streams for the Autism Advisory Service to employ additional Autism Advisors.
- Encourage cafes/shops to clearly indicate to their customers that they can support people who are neurodivergent and how they should let their staff know that adjustments are required.
- Implement a Zero tolerance for bullying and prevent inappropriate exclusion from social events
- Create groups for adults especially social clubs for diverse interests in spaces appropriate for autistic people due to noise and sensory stimulation (i.e. light, noise, volume of music)
- Make provision for autistic adults who received a late diagnosis and have different support needs to those who have had earlier diagnosis or who are without learning disabilities – an identified gap.
- Support local services for autistic adults who have “worked” or “lived independently.”

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Local Services

We will:

- Provide a range of activities covering the full spectrum including for autistic people with less complex needs, as most autistic people need contact with peers, access to one-to-one support and/or local clubs.
- Make needed adjustments for everyday services to increase accessibility to autistic people.
- Invest into activities and services adapted/adjusted to meet the needs of autistic people and to minimise sensory impact.

Transport

We will:

- Provide training for bus drivers, taxi drivers and escorts to know the needs of the autistic person and are trained in how to best to meet these needs and communicate with them.
- Provide additional support of getting driving licence for people with anxiety and sensory difficulties

Health

We will:

- Take action to tackle the over representation of autistic young people in mental health beds.
- Use Root Cause Analysis as part of the CTR/CETR process to address the expected high prevalence of autistic adults in inpatient mental health settings.

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care



What we will do as a partnership

Tackling health and care inequalities for autistic people

We will:

- Continue to work to reduce waiting times for assessment for children and young people. The project will continue to be monitored by the Berkshire Health Foundation Trust Board.
- In order to tackle morbidity and preventable death in individuals with autism, we will provide regular physical health checks and to maintain high level of clinical suspicion towards physical health problems in autism.
- Work at addressing issues related to adult assessments in order to bring the waiting times down.
- Work towards addressing the lack of a Positive Behaviour Service in order to get the service commissioned
- All organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West Clinical Commissioning Group NHS Autism and ADHD support service, as some parents, although sent a referral pack by the Autism Assessment Team (AAT), report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- All health and care organisations shall comply with their statutory duty under the Health and Care Act 2022 to ensure that all staff complete their Oliver McGowan Mandatory training in Learning Disability and Autism, so staff feel confident in supporting the individual needs of children, young people and adults with a learning disability and/ or autism.
- Focus on ensuring there are no barriers to accessing health services for people with a learning disability and/or autism, including access to age 14+ Annual Health Checks for those with autism and Learning Disability. The care they receive will be provided in a suitable environment, by people who understand their needs with suitable adjustments made when needed for them to receive excellent care.
- Through RBC commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation to prevent help prevent mental ill health in people with learning disability and/or autism

Building the right support in the community and supporting people in inpatient care

Support groups, services & Training

We will:

- Make available activities (across all ages), increasing social opportunities and social enterprise projects run by local people with lived experience.
- Provide training to adapt holiday clubs to be more inclusive and suit the needs of the autistic person
- Look at funding streams for the Autism Advisory Service to employ additional Autism Advisors.
- Encourage cafes/shops to clearly indicate to their customers that they can support people who are neurodivergent and how they should let their staff know that adjustments are required.
- Implement a Zero tolerance for bullying and prevent inappropriate exclusion from social events
- Create groups for adults especially social clubs for diverse interests in spaces appropriate for autistic people due to noise and sensory stimulation (i.e. light, noise, volume of music)
- Make provision for autistic adults who received a late diagnosis and have different support needs to those who have had earlier diagnosis or who are without learning disabilities – an identified gap.
- Support local services for autistic adults who have “worked” or “lived independently.”

Priority 4

Better lives: tackling health and care inequalities for autistic people and building the right support in the community, and supporting people in inpatient care

Social Experience

- There is a limited range of activities for autistic children, young people and adults.
- Many of the activities that are for young people are very good but limited and often they reach capacity very quickly e.g., Make Sense Theatre, Chance to dance.
- Young people have expressed they're not interested in competitive activities that require performing - saying they want to spend time with other autistic children.
- Activities like Holiday Clubs are difficult to access due to "not enough support personnel available". Families where both parents are working find the situation "hard".

A gap in provision was identified for autistic adults who have received a late diagnosis "and who have different support needs to those who have grown up knowing why they are different" or who are "without learning disabilities". Local services for autistic adults who have "worked" or "lived independently" are reported "non-existent".



Priority 5

Housing and independent living



Our Ambition

A culture that promotes neurodiversity and creates environments that meet the needs of autistic people and empowers everyone to reach their potential. Environmental respect, integrating rather than segregating and improving autistic lives in Reading.

What we know nationally

The National Strategy for Autistic Adults, Young People and Children: 2021-2026 prioritises housing as an area for improvement, to be achieved through activities including:

- Support for keyworkers for children and young people with complex needs in inpatient mental health settings, and those at risk of being admitted to these settings.
- Increasing the provision of supported housing, enabling more people to access adaptations to their homes and reforming the social care system so it is fit for purpose.
- 10% of the homes built via the new Affordable Homes Programme will be supported housing by 2026.
- Work with the National Body for Home Improvement Agencies to offer support to local authority DFG teams and work with autism charities to raise autistic people's awareness of how the DFG can support autistic people.

There is no one size fits all solution for housing for autistic people. This should be based on individual needs³². In an absence of a needs-led approach and appropriate support, autistic people may be faced with specific difficulties, and a higher risk of homelessness. Lessening barriers within the housing sector is of utmost importance to improve independence, wellbeing and quality of life.

NHS England's 'Building the right home' emphasises that alongside physical adaptations within homes, geographical considerations should be made, particularly where there are sensory needs, e.g., housing away from noisy streets, bright lights and considering triggers which could exist in the surrounding area³². Needs of the autistic person that may be linked to the proximity of established sources of support.

What we know in Reading

Locally, the number of autistic people that live within social housing is unknown, as it is not routinely monitored within the housing allocation and sign-up process. There is no specific pathway for autistic people within the housing system, rather, individual needs are considered throughout the process and support referrals made or adaptations may be made to homes. Considerations such as whether it is suitable for children to share bedrooms and space allocated accordingly, may be one such consideration. The Disabled Facilities Grant (DFG) is available for Homeowners, Private Tenants or Housing Association Tenants for adaptations to the home with the aim of making adaptations to live more independently. Within Reading, the DFG has been utilised to make adaptations for autistic people.

The homelessness service reports low numbers of autistic people presenting in need to the service, however, some individuals are placed in emergency accommodation such as bed and breakfasts due to lack of alternative temporary accommodation. This accommodation is often unsuitable for autistic people's needs and can result in disruptive behaviour and exacerbate vulnerabilities.

³² NHS England, LGA and ADASS (2016). Building the right home: Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display behaviour that challenges. Available at: NHS England report template cobranded-supporting partners

Priority 5

Housing and independent living

- Housing services within RBC do not have access to support in relation to autistic people that approach for homelessness assistance that don't meet the criteria for adult social care.
- Lack of emergency housing options within adult social care and not meeting social care thresholds, may result in autistic people being placed in inappropriate accommodation unsuitable for needs.
- General needs accommodation is not always suitable for all autistic people due to the responsibilities that come with managing a tenancy, there are risks that the pressure of living independently can lead to chaotic lifestyles potentially resulting in rent arrears, eviction and homelessness.
- Training for front-line housing staff is needed to better understand autistic people's needs.
- Clarity is needed on where autism sits within the adult social care and housing pathways
- Adult social care delivering safe accommodation options that are available for those with specific needs through a safe, easily accessible emergency account would be highly beneficial.

What is important to Reading people

Families and young people tell us that it is difficult to find information about what options are available and to obtain reliable support for a young person and adult in accommodation away from their family carers. Many parent carers provide an enormous amount of support to keep their autistic adult healthy and safe, sometimes at a cost to their physical and emotional health.

We asked autistic people and their families what is important to them about housing and what good housing should look like. Some of the responses are detailed below:

- The importance of feeling safe within their home - 'I don't want to move out of my parent's house, I like being there. I feel comfortable.'
- Maintaining their environment - 'I like everything to stay the same and I don't want to move.'
- An ideal home was described as being "tidy", with a "garden, lots of rooms and no noise from neighbours", in a "quiet and safe area" with "easy access to shops (with small wheelchair access) and green spaces" or "basic necessities". The home would be in easy reach of support such as 'housing officer', 'parents.' "On a main bus route" for regular bus schedules.
- For someone who needs "help with household chores", "supported living would be ideal" or "moving to a retirement place early".



Priority 5

Housing and independent living



What we will do as a partnership

Accommodation

We will:

- Improve data to help inform future commissioning of adapted / specialist housing.
- Support autistic adults to access suitable accommodation
- Include housing-related staff and providers in autism training plans
- Address the specific needs of autistic adults in future housing and homelessness strategies
- Make better use of existing specialist housing
- Ensure there is clearer identification by Brighter Futures for Children of the requirements for children within their current homes so that adaptations may be considered.

Independent Living

We will:

- Improve transitions planning to support independent living
- Implement needs led housing provision for autistic people
- Develop a clear shared strategy for provision of supported accommodation for autistic adults
- Plan to increase investment in aids, adaptations and new technologies which support independent living.
- Develop innovative models of accommodation with agile care and support options including reablement.

Training

We will:

- Increase the number of trained support workers to run activities in the community

Priority 6

Keeping safe and improving support within the criminal and youth justice system



Our Ambition

Greater awareness of the impact of autism on risk and need for autistic people involved with the Criminal Justice System (CJS).

What we know nationally

There is evidence that autistic people often have challenging, poor experiences when they encounter the CJS. Reasons cited include a lack of awareness, confidence and understanding amongst CJS staff and challenges surrounding adjustments required for autistic people to engage in processes.³³ It is the responsibility of local authorities under the Care Act, to assess all resident's needs, inclusive of those in prisons and ensuring that adequate support systems are in place for them. The National Autistic Society states that autistic people are more likely to be witnesses and victims of crime than offenders.

Certain features of autism may predispose young people to offend or be victims of crime, including social naivety, misinterpretation of social cues and poor empathy. Most evidence indicates overrepresentation of autistic people within the CJS, in particular the publication *Nobody made the connection: The prevalence of neurodisability in young people who offend by the Children's Commissioner*, identified a study which reported the prevalence of autism within youth custody, and suggested an incidence rate of 15% compared to the estimated 0.6 to 1.2% of autism diagnosis in the general population.

What we know in Reading

- Reading has a Police Station, but the custody suite is located at Loddon Valley Police Station. Reading has a Magistrates and Crown Courts and a Probation office, but no prisons or Young Offenders Institutes.
- The CJS is not required to record autism as a condition. Where data was available, a limited analysis of the prevalence of autistic people in Reading was possible.
- Where a person has an autism diagnosis, there are challenges within the different information systems used by Police, Courts, Prison and Probation to transfer the information appropriately.
- In Reading we have the Liaison & Diversion (L&D) service based at Reading courts and at custody at Loddon Valley, that aims to identify people when they first encounter the CJS if arrested or charge, who may need additional support due to mental health, disability, substance misuse or other vulnerability. The service can assess needs, inform criminal justice decision-making and aid in people accessing the appropriate health and social care support as they move through the CJS, and enable people to be diverted away from the CJS into a more appropriate setting, if required.
- Health partners highlighted a lack of appropriate provision within the community post secure system, although the Ministry of Justice is undertaking a tender process in Spring 2022 for an autism support service.
- Families are advised by both Children's Social Care and CAMHS to contact the Police if their autistic child or young person are aggressive to them and they do not feel safe. However, parents have not wanted to call the Police, and when they have done some parents have reported it has not been helpful.
- Currently there is no Positive Behaviour Team to support parents whose autistic children have violent and challenging behaviour. It has been agreed this is a gap in services, and the local NHS commissioners, Berkshire West CCG had run a commissioning process in Spring 2022, but not awarded a contract.
- Reading has a multi-agency partnership to improve outcomes for children, the One Reading partnership includes

³³ S.B. Helverschou, K. Steindal, J.A. Nøttestad, P. Howlin. Personal experiences of the Criminal Justice System by individuals with autism spectrum disorders. *Autism*, 22 (4) (2018), pp. 460-468, 10.1177/1362361316685554

Priority 6

Keeping safe and improving support within the criminal and youth justice system

Thames Valley Police, Reading Borough Council, Brighter Futures for Children, Royal Berkshire NHS Foundation Trust, and Reading Voluntary Action. They have produced the One Reading Young People and Extra Familial Harm Strategy 2021/22 to 23/24 which sets out how the partnership will work together across agencies and with young people and communities to prevent and respond to extra familial harm and keep young people safe in their communities.

- Autism Berkshire launched the Berkshire Autism Alert card in 2010 as a quick and easy way for someone to identify that they were autistic, and over 2000 cards were issued. In 2020, the scheme was updated to include a new online application process and the ability to share information with Thames Valley Police if the individual wished to. In 2021, the card was updated to the Thames Valley Autism Alert card to cover Buckinghamshire, Oxfordshire and Milton Keynes as well as Berkshire, and there are now more than 700 of the new cards in circulation including 200 issued to Reading residents during the 2021-22 financial year. Autism Berkshire has a data sharing agreement with Thames Valley Police and is supported by the Thames Valley Police and Crime Commissioner.

What is important to Reading people

- To prevent offending and support rehabilitation and inappropriate involvement with the CJS, early identification and support to prevent entry into the CJS is vital.
- Ongoing use of and awareness raising of the Thames Valley Autism Alert Cards to appropriate services is encouraged.
- It is acknowledged that within the CJS the system is improving surrounding autism, as there is greater recognition, less stigma and better access to care, compared to some years ago.

Case Study 1:

Youth Criminal Justice Liaison and Diversion Service, Assistant Psychologist

Reason for Referral

Jay was referred to the Berkshire Healthcare NHS Foundation Trust's Youth Criminal Justice Liaison and Diversion Service (YCJL&D) by a Forensic Paramedic who saw him in custody when he was arrested for being concerned in the supply of Class A drugs. He was 'Released Under Investigation' for this matter.

The YCJL&D service completed an assessment with Jay and his mother at the family home. The assessment indicated that Jay experienced difficulties with low mood and substance misuse. He was not engaged in Education or Training (NEET) and was not participating in any regular enjoyable activities. In addition, his mother was very open about experiencing low mood herself, chronic pain and the family were experiencing financial strain. Jay's Mother was not in receipt of Personal Independence Payments (PIP) or Employment Support Allowance (ESA). Jay was not in receipt of Carers Allowance, despite providing a significant caring role for his mother. Due to a mistake made by the Housing Association, the family were left with limited means to purchase food. Jay enjoyed football and was motivated to engage in education or training. Jay and his mother benefit from a close relationship and she demonstrated a sensitive understanding of his needs.

Priority 6

Keeping safe and improving support within the criminal and youth justice system

The YCJL&D service supported Jay's mother to complete a self-referral for Talking Therapies. Over coming weeks, the YCJL&D Assistant Psychologist (AP) completed referrals to the Specialist Mental Health Team and 'Source', which is the youth Drug and Alcohol Service provide by the local Council. Also, a referral was made for Jay to attend an Education Provision within a local sports club. Support was additionally given to assist Jay's Mother to apply for PIP and ESA. Whilst Jay's Mother was awaiting an appointment for a PIP face-to-face interview, we referred the family to the local food bank who delivered weekly parcels of food and toiletries.

Outcomes

When the mental health referral was triaged, it was recommended that Jay was supported by a clinician from Source as it was felt that his mental health needs were secondary to his issues with substance misuse. In the weeks leading up to his first appointment, our Assistant Psychologist provided weekly individual sessions to Jay to provide short-term psychological support focussed on psychoeducation about mood and stress, sleep hygiene and scheduling enjoyable activities. Jay engaged well with the clinician from Source and they completed the appropriate work to support him in reducing his drug use.

The referral for Jay to attend an Education Provision within a local sports club was accepted. He attended the 12 week course and completed it, receiving his qualifications and inviting the YCJL&D service along to his graduation. Jay's mother's PIP application was accepted and she was back paid for 3 months. We then supported Jay in applying for Young Carer's benefits, which were also accepted and he too was back paid for 3 months..

Jay's Mother attended Talking Therapies and found the support offered by them very useful.

YCJL&D had contact with Jay 10 months after the case was closed to the service, and Jay tells us that he is working night shifts at a local fast food restaurant and completing a plumbing apprenticeship with the local college. He reports that he and his mother are doing really well and he has had no contact with the police since.

We asked Jay and his mother a few questions on their experience with YCJL&D:

1) What have you found most useful about the Youth Criminal Justice Liaison and Diversion Service "Everything!" Jay and his mother report that the YCJL&D service have been the only "people that have listened" to them properly. Jay's mother reported "the amount of pressure that you've taken off me is immense". Jay reported that he is pleased to be engaged with an education sports programme. Jay was glad that we could help his mother with the more practical help, such as letters, benefits and phone calls as he feels he doesn't understand it all.

2) What do you think would be different if the YCJL&D did not have an input? Jay's mother said that they'd be 'homeless' due to the fact that they would have kept on struggling with their relationship, they felt that Jay would have carried on getting arrested as well. Jay's mother reported "We're off the merry-go-round and it's stopped", she reports that the merry go round is negative and they finally have some positives in their lives.

Jay and his mother took part in the making of a short film that tells their journey with the Youth Criminal Justice Liaison

Priority 6

Keeping safe and improving support within the criminal and youth justice system

and Diversion Service. With reassurance that only proportionate information from his clinical assessment would be shared together with his progress in the form of a report, consent was given by Jay and his mother to share information with criminal justice decision makers. Jay was invited in for a voluntary interview with the police for the offence. In recognition of the work that he completed, and the progress made, he was given a caution for possession of Class A drugs.



What we aim to do as a partnership

We will

- Support Autism Berkshire in the continued roll out of the Thames Valley Autism Alert card.
- By supporting this collaboration work with Thames Valley Police and Autism Berkshire, officers will be better equipped, so that any interactions should be more positive for all concerned.
- Work with partners so there is a much wider understanding of “county lines”, “mate crime” and “cuckooing” within all sectors and the wider community and provide a multi-agency response to the victim. The One Reading Young People and Extra Familial Harm Strategy 2021/22 to 23/24 covers these types of crime.
- The crime type itself will be better understood by partners and the community and the support package provided will be tailored to the needs of the victim to prevent and protect going forward.
- Work with partners to better understand the representation and needs of Autistic people within the Criminal Justice System. And ensure they are aware of and using the registered intermediary where appropriate.
- By effectively understanding the demand we will be better placed to provide support where appropriate.
- Make universal use of a consistent screening tool within the Criminal Justice System is needed along with an information sharing protocol for information sharing between services.

In order for autistic young people and adult to keep safe:

We will:

- Through our commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice and guidance, and activities to reduce loneliness and isolation.
- Support people who are vulnerable, including teaching anti-victimisation and personal safety skills.
- Support autistic people with paid employment and fixed activity routines, that they feel safe and confident doing, thus minimising the risk of vulnerabilities being exploited by others
- Mainstream services/local organisations will work in partnership with Prevent/Channel to identify those at risk of being drawn into extremism, assess and offer appropriate support plans to suit individual’s need

Priority 7

Improving support for families and carers

Aligns with Reading's SEND Strategy:

Strand 5: Support for families / short breaks



Our Ambition

Understanding and tailored support and communication so that autistic people, and their families and carers are enabled to live their healthiest lives to the fullest, throughout their life span.

What we know nationally

Families and carers of autistic people are often key to people being able to live independently in community settings. However, supporting another person, often for many years, can place a great deal of strain on the carer, especially if the person with autism does not want outside support, or struggle to engage with services or new people.

National picture

There are an estimated 3 million family members and carers of autistic people in the UK³⁴

Some autistic people will need very little or no support in their everyday lives while others need high levels of care, such as 24-hour support in residential care. The National Strategy for autistic children, young people and adults aims at putting in place effective measures to 'make a difference to autistic people and their families' lives' and for their life to be 'fundamentally better.'

The Government has also pledged to provide support to facilitate engagement, including supporting Parent Carer Forums, to strengthen the engagement of parents and young people in the Special Educational Needs and Disability (SEND) system, the Transforming Care for Children and Young People accelerator programme, and a review of advocacy for families and carers to be able to speak up about the experiences of their loved ones.

The Care Act 2014 has given carers of adults the same rights as those they care for – the right to a carer's assessment and support plan if they have eligible needs and a personal budget, as well as information, advice and guidance on support available or that they are entitled to (e.g., carer's breaks) and how to access this. In Reading this can be provided through social care or the Reading Carers Hub. Under the Children and Families Act 2014, the Council has a duty to assess parent carers on the appearance of need or where an assessment is requested by the parent. The assessment covers the health and wellbeing of the parent carer and the need to safeguard and promote the welfare of the child cared for. The Council must be satisfied that the child and their family come within the scope of the Children's Act 1989.³⁵

What we know in Reading

- Parents and carers need to be supported and feel supported at the outset even whilst a child, young person or adult is waiting for an assessment as the waiting lists in Reading are significantly

³⁴ Local Government Association (LGA) (2022). Support for autistic people | Local Government Association. [online] [www.local.gov.uk](https://www.local.gov.uk/our-support/sector-support-offer/care-and-health-improvement/autistic-and-learning-disabilities/autistic#:~:text=It%20is%20estimated%20that%20there). Available at: <https://www.local.gov.uk/our-support/sector-support-offer/care-and-health-improvement/autistic-and-learning-disabilities/autistic#:~:text=It%20is%20estimated%20that%20there>.

³⁵ National Autistic Society (2020b). Carers assessments in England. [online] www.autism.org.uk. Available at: <https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/carers-assessments>.

Priority 7

Improving support for families and carers

- longer than the 13-week NICE guideline.
- Reading has a wide range of voluntary groups/organisations that offer support for autistic people with or without a learning disability, and their families. Details are on the Reading Services Guide and the Local Offer.
- The Berkshire West Autism and ADHD Support Service has been commissioned by Berkshire West CCG and co-produced by stakeholders in health, education, social care and the voluntary sector. It is run by Autism Berkshire and delivers autism support for families and carers whilst they wait for their child or young person to be assessed or after diagnosis (see Priority 4)
- The Autism Berkshire service encompasses advice, support and workshops for families, of children and young people aged 5 to 25 who may or may not have Autism or ADHD or are waiting for assessment. Advice & strategies cover topics including child development, speech, play, food issues, toileting, sleep, supporting behaviour, sensory issues, puberty and supporting anxiety. Autism Berkshire also support parents in navigating the school and social care system.

The service includes a Helpline, one to one consultations and workshops:

- Home Visits – an in-depth one-to-one discussion online or face-to-face (where possible) with parents and carers
- Autism advice workshops: online workshops lasting 2 hours Understanding More About Autism; Sensory Differences plus Plan and Q and A session; and Supporting Behaviour plus Plan and Q and A session, parents can attend one or all three
- Teen Life, a National Autistic Society 6 week course for parents and carers of autistic children aged 10 to 16. Includes a workbook which parents can refer back to after the course.
- Additional workshops/webinars for parents and carers cover: Autism and Girls, with autism advocate Carly Jones MBE, Emotional Regulation, Food Refusal, Sleep Difficulties, Transitions to Adulthood

Support for children and young people includes:

- Tailored interventions, based on individual need, for children aged 5 to 7
- Social interaction skills groups for children/young people 8-16, to develop confidence and emotional wellbeing (run by Parenting Special Children)
- SocialEyes, a NAS course for autistic 17 to 25-year-olds, looking at further social interaction skills and strategies to boost wellbeing and independence.
- Parents can self-refer to the Autism Berkshire service using an online form Berkshire West Autism & ADHD Support Service referral form for parents, carers and autistic young people - Autism Berkshire this includes consent to store their data and to receive the newsletter.
- Professions can refer families Berkshire West Autism & ADHD Support Service referral form for professionals - Autism Berkshire Both referral forms are secure and comply with the NHS Data Protection and Security Toolkit.
- Short breaks are opportunities for children and young people with disabilities to spend time away from their families and carers, socialise with peers and have fun as well as provide opportunities for families and carers to have a break from caring responsibilities.
- Brighter Futures for Children commission a range of Short Breaks. These are advertised via the Local Offer³⁶ and are either free or subsidised. Currently we have a performing arts, dance, football, Lego and independence Short Breaks running.

³⁶ Special Educational Needs & Disabilities - Reading's Local Offer | Reading Services Guide

Priority 7

Improving support for families and carers

- The Local Offer also listed other activities for children with SEND including autism. Parents can use the Local Offer website or phone to speak to one of the very knowledgeable staff.
- The Local Offer staff can help families with individual queries, for example finding a SEND childminder or a Short Break for a child with a special interest.
- For children who have been assessed by a qualified social worker in line with Section 17 Children Act 1989 as being eligible for services as Child in Need may be eligible for an overnight residential Short Break service at Cressingham. This is for no more than 75 nights per year away from their families. The referral route to this service is via Brighter Futures for Children Single Point of Access (available online).
- For children who have been assessed by qualified social workers to need more than 75 nights per year of care away from their parents may be eligible for shared care at Pinecroft residential accommodation. The children are resident without their parents and have weekly and regular nights at Pinecroft to enable parents and siblings to have a break. Cressingham and Pinecroft are regulated childcare provisions and are managed by Brighter Futures for Children and regularly inspected by OFSTED with Cressingham rated Outstanding and Pinecroft Good at the last inspections in 2021.
- Pinecroft has been remodelled with a new sensory room and outside space. An Open Day was held in Spring 2022 and well attended by families and professionals.
- RBC's Adult Social Care team run a Preparing for Adulthood Team to support families when their child moves from children's to adult services. See section 2.
- Reading Mencap runs a highly regarded Family Adviser service providing information, advice and guidance, to support adults with Learning Disability and Autism, and their families, including advice about daily living, helping maintain a tenancy, health appointments and access to statutory services, including benefits. RM employ a specialist Transition Family Adviser.
- Reading Mencap runs day services and clubs for people with a Learning Disability, or a Learning Disability and Autism to reduce loneliness and isolation and improve mental wellbeing, and provide respite for carers:

2 day services of 7 hours a day with 60 places each service

1 weekly x Self Advocacy day-time club

1 x monthly evening disco

2 x Gateway evening Clubs

1 x evening Performing Arts Group

1 x 5 hour Saturday Daytime Transitions club 18-25 (awaiting a start date)

Quarterly carers coffee mornings

- The Whitley Wood respite service is available to learning disability and autistic adults and is run by Reading Borough Council. It was rated Good at its last inspection by the CQC in 2017.
- Tuvida Carers Hub is commissioned by Reading Borough Council and BFFC to provide support to adult carers, including information, advice and guidance, respite breaks or crisis support with the Carers Break service.
- Parents and family carers can access the Reading Carers Card, allowing carers to be identified at various local outlets for easier access and targeted support.
- Carers can request a carer's assessment of their needs to identify areas where they need additional support or explore opportunities to improve their health and wellbeing. This could be through allocation of a personal budget specifically for the carer to use for an activity of their choice.
- Reading Families Forum (RFF) is funded by government grant and is an independent charity run by and for families of disabled children and young adults aged 0 – 25 years. RFF are part of the National Network of Parent Carer Forums. They

Priority 7

Improving support for families and carers

work to ensure that local parent carers and young people with all additional needs co-produce local services that they use. Co-production means that families are at the heart of discussions, giving their views and experiences about what is needed and setting priorities.

- COVID-19 measures taken to reduce the spread of the virus have limited access to many services, including respite care. These services are now re-opening, but many carers have gone without a break for many months and are in great need of time off to recuperate.

What is important to Reading people

We spoke to Reading parents and carers and found that less than 10% of respondents felt supported by statutory health, care services and voluntary community sector services in their caring role.

Some needs identified included the below:

- o Facilitate access to breaks for families and carers
- o Better child-care provision and activities during half-term and school holidays or weekend clubs needed for primary school age children
- o Improve communication to keep parents informed of progress or additional services available



What we aim to do as a partnership

We will

- Through our commissioning of Closing the Gap, and our small grants scheme, we will support organisations to provide information advice, guidance, and activities to reduce loneliness and isolation.
- Through commissioning of the new carers service later in 2022, we will support carers and families to access carers assessments, information, advice and guidance, respite and crisis support and more easily.
- In order to support carers better, all organisations will refer all parents needing pre-assessment or post-diagnosis support to the Berkshire West CCG NHS Autism and Attention Deficit Hyperactivity Disorder (ADHD) support service, as some parents, although sent a referral pack by the Autism Assessment Team (AAT), report not knowing about the support available either, whilst they are waiting to be assessed, or after diagnosis.
- To support carers better, all organisations will refer all parents to the Local Offer, so they can access information and signposting, as some parents are reporting that they are unaware of the service.
- Brighter Futures for Children, Adult Social Care, the Local Offer, Reading Services Guide, and Autism Berkshire and Reading Mencap will promote the ordinarily available, and specialist autism and learning disability services to families and carers.
- Brighter Futures for Children will review the provision of Short Breaks to ensure it meets the needs of families

7.0 Delivering our future priorities

Reading's multi-agency Autism Board must be supported to ensure that key work and insights contribute to timely, appropriate provision of services and resource for Reading's population of autistic people and those that support them.

Local Governance and Monitoring Arrangements

Progress made against the priorities, associated actions and any commissioning intentions set out in this strategy will be formally reported to and monitored by:

- Autism Board
- Health and Wellbeing Board

Using existing networks and partnerships the work included in this strategy's implementation plans will be communicated and updates provided to:

- Autism Board
- SEND Standards Board
- Health and Wellbeing Board
- Community Safety Partnership Transitional Care Partnership
- Learning Disability Partnership Board
- Mental Health Forum
- MH/LDA ICP Board and CYP ICP Board

The Autism Partnership Board - will lead on co-ordinating the implementation of the strategy through developing implementation plans and measures of success to support priorities across partners to achieve the planned outcomes, provide answerable leadership in partnership with all partners with the duty, knowledge and desire to improve the lives of autistic people and their families and carers. This board will consist of key stakeholders from across the system including autistic people and family representatives. The board will further define monitoring arrangements.

This strategy and implementation plans are live documents which will be used to monitor progress and work with partners to drive positive outcomes for autistic people and their families. A significant joint effort will be needed. As live working documents, the implementation plans will be updated to reflect any changes to need and develop as the strategy progresses.



NHS
Buckinghamshire, Oxfordshire
and Berkshire West
Integrated Care Board

