



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



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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 2022 and the two documents are intended to complement each other.

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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)

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 others¹. 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 disability^{3,4}. Within this strategy, we also talk about neurodiversity.

Neurodiversity

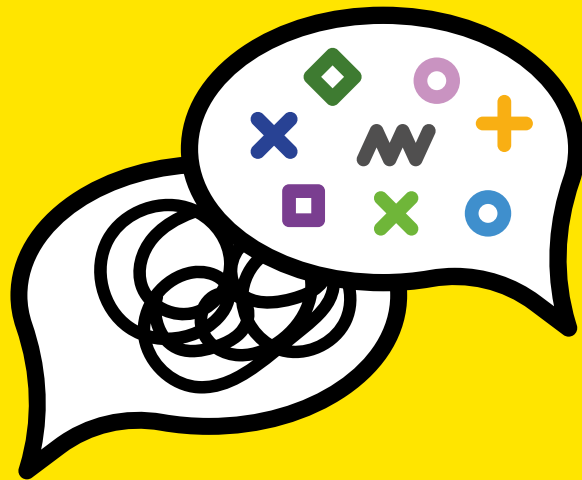
Neurodiversity is the fact that all human beings vary in the way our brains work.

- 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.

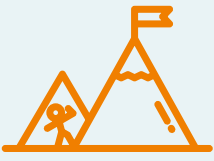
¹ National Autistic Society (2020). What is Autism? [online] Autism.org.uk. Available at: <https://www.autism.org.uk/advice-and-guidance/what-is-autism>

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, young people, and adults^{6,7}.

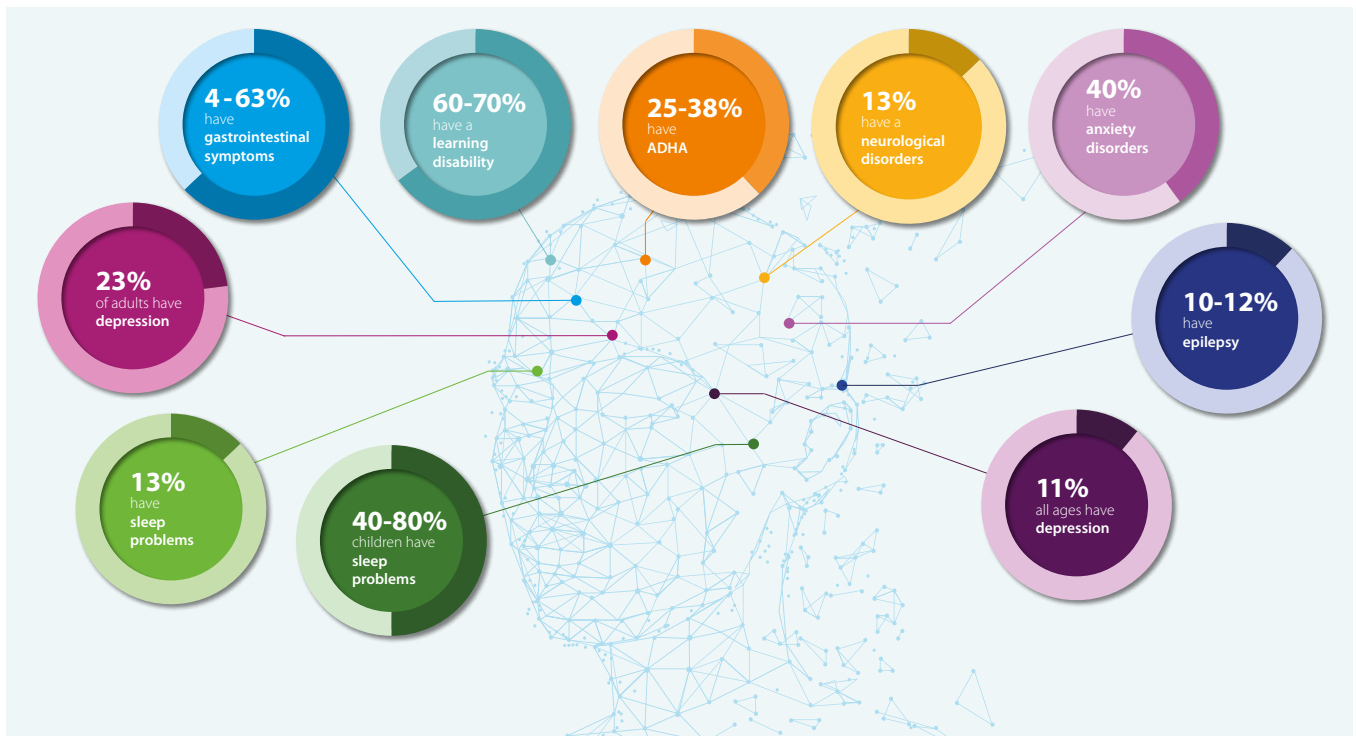
⁶ Brighter Futures for Children (2021). A growth approach to autism. [online] Brighter Futures for Children. Available at: <https://brighterfuturesforchildren.org/professionals/school-standards-services/school-standards-service-a-growth-approach-to-autism>

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>.

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. 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.

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 \(autism.org.uk\)](http://Varying support needs (autism.org.uk))

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

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, 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



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 of all ages 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 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.

Priority 1

Improving awareness, understanding and acceptance of autism within society

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 Voluntary Community Sector.

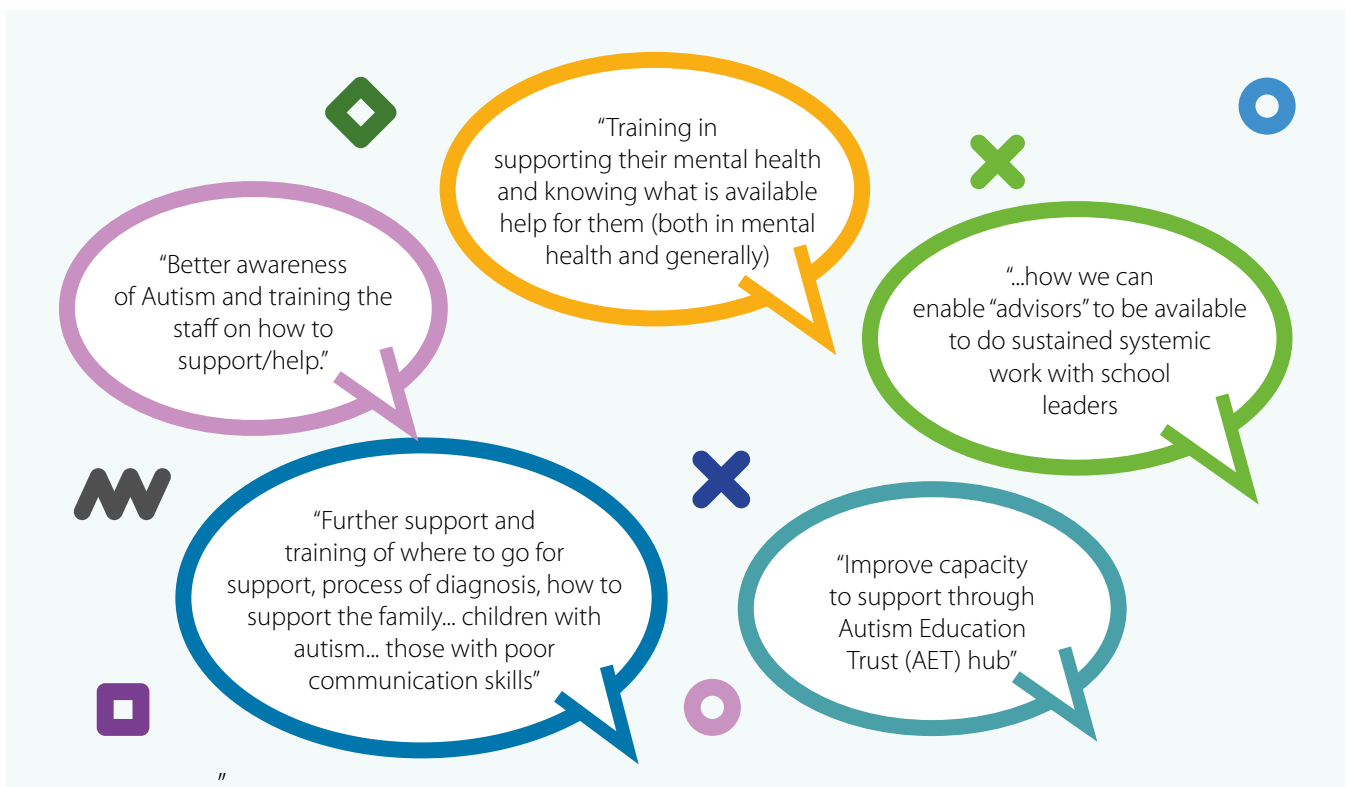
Priority 1

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

Planning:

- Expand Autism Board to improve representation (autistic children, young people and 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:

- Develop a comprehensive multi-agency training plan to ensure early years, educational settings and 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 & 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 an 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 assessment and post diagnosis 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, supporting positive transitions and preparing for adulthood



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).
- 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.

Priority 2

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

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

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

A recent study reported that young autistic ethnic minority groups from lower income backgrounds were less likely to receive

Priority 2B

Supporting Transition and Preparation for Adulthood

health care transition services, participate in transition planning meetings, enrol in postsecondary education, find good employment after school or live independently compared to their autistic Caucasian higher income counterparts.

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 services¹¹.

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

¹¹ 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

Covering Priority 2 and 2b

Culture change

- Tackle bullying within schools, isolation, and inappropriate exclusions.
- As well as awareness raising in schools, additional measures to be implemented 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 to help autistic young people to find the right opportunity.

Transitions & Diagnosis

- Strongly encourage schools share information they receive about local support and activities – need to ensure this information is shared with all children/families with additional needs.
- Ensuring 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 and social care after turning 18 and when finishing school or college, if later.
- Improve transitions planning for all (education/social care/health) children and adult services – more work to be done so Young People and family are provided with robust information to support.
- Supporting people into adulthood through volunteering opportunities
- Create additional internships, apprenticeships and meaningful work experience for young people and adults which enhance prospects for autistic people.
- Supporting smooth transition to adult services for young people including support for adults where needed.
- Ensuring data collection and audit of the diagnosis pathway takes place⁸.

Priority 3

Supporting more autistic people into vocational training and employment



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 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

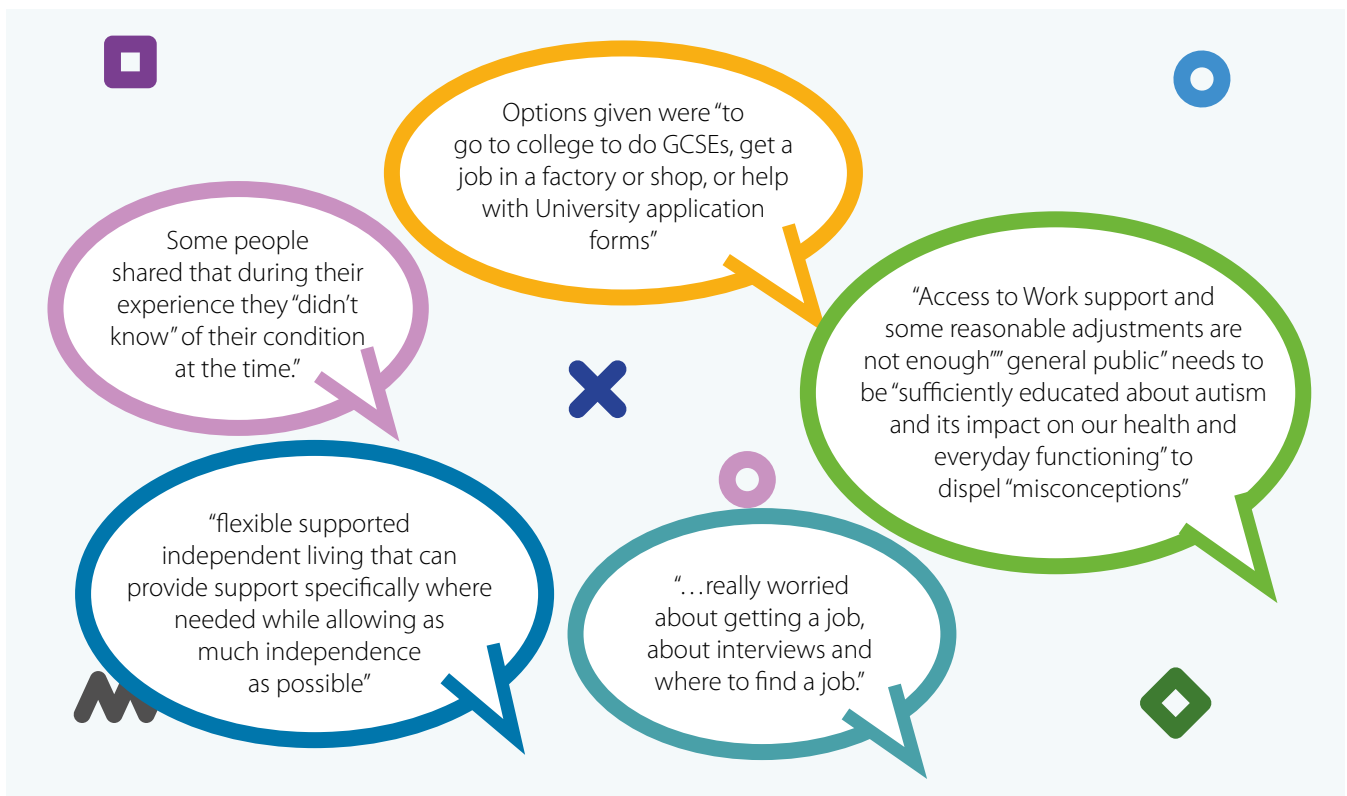
Training and Employment

- 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

- Increase volunteering opportunities
- Identify the strengths and needs of neurodivergent CYO 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 through a coproduced approach with autistic people.
- 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 to get into employment and 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 & employment assistance for those over 25
- Support for 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 for autistic people: tackling health and care inequalities and building the right support in the community, and supporting people in inpatient care



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.
- 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.

Priority 4

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

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.
- 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 concerns¹².
- 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.

¹² Mental and Emotional Health | Children Young People and Families Online Resource (berkshirehealthcare.nhs.uk)

Priority 4

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

- 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 appointments¹³.
- The Royal Berkshire Hospital also has a series of Easy Read leaflet for patients with Learning Disability and Autism available on their website¹⁴.
- Many of Reading's GP have included details of the Berkshire West Autism and ADHD Support Service on their website under the Wellbeing section¹⁵.
- 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

¹³ Your information and what we use it for (royalberkshire.nhs.uk) this should say Use the Bleep

¹⁴ Disabled Patients | Royal Berkshire NHS Foundation Trust contains a list of Easy Read leaflets for LDA patients

¹⁵ Autism | Balmore Park Surgery

Priority 4

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

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 autism¹⁶.

What is important to Reading people

- Better awareness of what autism is and the environmental/sensory impact on autistic people within healthcare settings.
- Assessment waiting times 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 aim to 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 Berkshire Health Foundation Trust board.
- 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 autism¹⁷.
- 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 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, we will aim to 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.

¹⁶ Our Neurodiversity Strategy | Berkshire Healthcare NHS Foundation Trust

¹⁷ Sala et al (2020)

Priority 4

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

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 encouraged¹⁸. Interventions focused on life skills/activities of daily living e.g., leisure activity programmes 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%¹⁹ while autistic people account for 1 in 100 people.

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 has a vibrant transport system and an award-winning transport company Reading Buses, owned by the

¹⁸ <https://www.nice.org.uk/guidance/cg170>

¹⁹ 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 for autistic people: tackling health and care inequalities and building the right support in the community, and supporting people in inpatient care

Borough Council. Reading Buses are ranked as one of the most accessible in Europe, with colour coded buses and maps to help people easily navigate bus routes. Reading Buses are committed to accessibility. All buses are equipped with wheelchair ramps, high contrast strips on the floor and the seats, braille on the bell pushes, next stop announcements and next stop video signs, route maps on the bus. There is a bus app with timetables, maps and ticketing available. It also has a bus tracker, useful for when people are learning to travel independently.

- All bus drivers take part in disability training as part of their Certificate of Professional Competency and Reading Buses have worked closely with local charities such as Autism Berkshire, to implement a driver training course to learn about the needs of autistic people.
- Reading Station, managed by Network Rail, offers an assistance service to passengers with additional needs, including autistic people. A new travel lounge at the station opened in July 2021 for 'Passengers with additional needs'. Station users can also pre-book journey assistance with all their needs considered, including a Quiet carriage, changes and connections that involve other train companies.
- 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 local community transport provider. Readibus is a Dial-A-Ride bus service is for people of all ages who can't make use of the mainstream bus services offered in the area. This includes autistic people who have high anxiety or sensory issues. Readibus was judged in the 'Community Transport Provider of the Year' category at the Community Transport Awards in November 2021 as one of the top three community transport services in the UK for its service provision during the pandemic, and the best in England.
- Readibus is the specialist service used for School Transport, mostly for wheelchair users but provides 6 buses for the Avenue School – and an ambulance for the most complex needs pupils.

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



What we aim to do as a partnership

Support groups, services & Training

We will:

- Increase availability of activities (across all ages), social opportunities and social enterprise projects run by local people with lived experience including online community options and opportunities outside of core business hours for autistic people
- Provide training to adapt holiday clubs to be more inclusive and suit the needs of the autistic person
- Look at funding streams for 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.”

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 needed 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.
- Using 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 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.

We embed a greater understanding of how neurodivergent people experience the built environment in different ways, and how choices made within streets and spaces may affect people differently, for instance in terms of colours, materials, patterns and levels of visual clutter.

What we know nationally

The National Strategy for Autistic Adults, Young People and Children: 2021-26¹¹ 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 needs²⁰. 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 area³⁴. 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.

²⁰ 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

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.

- 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 aim to do as a partnership

Planning:

- Take account of best practice guidance in developing policies for the built environment including the Local Plan Review and Public Realm Strategy.

Accommodation:

- Improve data to help inform future commissioning of adapted / specialist housing through joint action
- Involve local partners to ensure autistic adults supported 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 BFFC of the requirements for children within their current homes so that adaptations may be considered.

Training

- Increase the number of trained support workers to run activities in the community
- Work towards increasing availability of activities across all ages.

Priority 6

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



Our Ambition

Greater awareness of the impact of autism x 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 processes²¹. 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 is important to Reading people

- 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.

²¹ 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

- Reading has a multi-agency partnership to improve outcomes for children, the One Reading partnership includes 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.

Areas 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, Molly Scott, 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.

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

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

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 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.

Priority 6

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



What we aim to do as a partnership

- 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 a 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 CJ 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.
- Universal use of a consistent screening tool within the CJS is needed along with an information sharing protocol for information sharing between services.

For autistic young people and adult to keep safe, we will:

- Through our commissioning, we will aim to 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 to 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 needs.

Priority 7

Improving support for families and carers of autistic people



Our Ambition

Understanding and tailored support and communication so that autistic people, and their families and carers of children, young people and adults 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.

Caring for an autistic person can be rewarding but also demanding, both mentally and physically, and often isolating. Carers can benefit from training to help them better understand autism, support to plan for the future, peer support and opportunities to take breaks from caring.

National picture

There are an estimated 3 million family members and carers of autistic people in the UK²².

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 person cared for. The Council must be satisfied that the child and their family come within the scope of the Children's Act 1989²³.

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 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.

²² 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>

²³ 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

- 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 Offer²⁴ and are either free or subsidised. Currently we have a performing arts, dance, football, Lego and independence Short Breaks running.
- 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

²⁴ Special Educational Needs & Disabilities - Reading's Local Offer | Reading Services Guide SEND Local Offer page

Priority 7

Improving support for families and carers

- 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.
- 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 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.

Priority 7

Improving support for families and carers

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:

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



What we aim to do as a partnership

- Through our commissioning, we will aim to 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.
- To support carer better, 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.
- 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

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.

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