

Reading's Autism Strategy for Children, Young People and Adults

2015 - 2018

Contents

Introduction.....	2
Developing Reading’s Autism Strategy	2
The Structure of this Strategy	3
What is Autism?	4
What have people with autism told us?.....	5
National Context	5
Local Context	6
Autism in Reading - Local Profile and Needs Analysis	8
Current Services and Support for People with Autism.....	11
Children and Young People.....	11
Adults.....	13
Priority 1 - Increasing Awareness and Understanding of Autism	15
Priority 2 - Improving Access to Diagnosis & Beyond	17
Priority 3 - Supporting Better Life Outcomes for People with Autism	19
Priority 4 - Supporting People with Autism to Live Safely and as Independently as Possible	22
Priority 5 - Supporting Families and Carers of People with Autism	24
Priority 6 - Improving how we Plan and Manage Support	25
Delivering the Strategy.....	27
Improving Outcomes for People with Autism	28

Introduction

Autism is a condition that affects people in a variety of different ways and degrees. Reading Borough Council is committed to improving the lives of people with autism living in the town. This Strategy sets out how we aim to achieve this, through our own commissioning and delivery of services and our close working with partners locally.

This is a broad strategy that covers all autistic people, across the spectrum. It is a “life-long” Strategy that considers children, young people and adults, as well as the wider impacts for their families and carers. For people with autism who are assessed as eligible for statutory support from social care or health services, the Strategy explains how we will ensure their needs are met in a consistent and person-centred way. However, we recognise the importance of support that is available to all people on the autistic spectrum, and the key role of universal services and preventative or low-level support. One of the aims of this Strategy is to encourage all services and organisations to “think autism”, maximising the opportunities to better support autistic people in Reading.

A range of partners across the public sector (including health services), private sector (such as providers of care and support) and the voluntary, community and faith sector already work together to support children and adults with autism and their families and carers. At a time of reducing budgets across public services, we need to strengthen this partnership working even further. There is no new money to deliver this Strategy, and so the focus for the actions identified is making the most effective use of existing resources. This might mean reshaping current provision and taking creative approaches towards the use of resources across partners to continue to develop our services. Autistic people and their families and carers are central to this service development, and their involvement is key in shaping and delivering services, such as informal or peer support.

Developing Reading’s Autism Strategy

In 2013, Reading Borough Council commissioned Berkshire Autistic Society (BAS) to carry out an assessment of the needs of people with autism locally and the services available. This needs assessment and the recommendations from the work have informed the development of Reading’s Autism Strategy. The needs assessment included a survey with autistic people and their carers and families. Feedback from people with experience of living with autism in Reading was central to the development of Reading’s Strategy.

The Autism Strategy was drafted during 2014, with input from a wide range of stakeholders to make sure that the Strategy represented the work of the variety of

services and organisations that support people with autism. The Autism Strategy Steering Group of key partners has helped with the detailed work on the Strategy, such as ensuring that it aligns with existing work in other areas.

We would like to thank the many people and organisations that have been involved with the development of the Council's Strategy. This list is not exhaustive, but some of those involved include:

- Reading Borough Council staff and councillors
- People with autism, their carers and families
- Berkshire Healthcare NHS Foundation Trust
- NHS Central Southern Commissioning Support Unit (for North & West Reading and South Reading Clinical Commissioning Groups)
- Autangel
- Berkshire Autistic Society
- Reading Children's & Voluntary Youth Services
- Reading Families Forum
- Reading Mencap
- Talkback

The Structure of this Strategy

The Strategy presents some clear actions aimed at improving support for autistic people in Reading. These are identified in the boxes throughout the Strategy organised by the six priorities that are identified for improving support for people with autism in Reading:

1. Increasing awareness and understanding of autism
2. Improving access to diagnosis & beyond
3. Supporting better life outcomes for people with autism
4. Supporting people with autism to live safely and as independently as possible
5. Supporting families and carers of people with autism
6. Improving how we plan and manage support

The final part of the document sets out how we plan to deliver the Strategy through the development of an Action Plan to be overseen by Reading's Autism Partnership Board.

What is Autism?

The term “autism” is used in this Strategy as an umbrella description for all autism conditions, including Asperger Syndrome, that fall under the headings of Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC). Autism is a lifelong developmental disability that affects how a person communicates with and relates to others, how a person learns and makes sense of the world, and processes information. People who are on the autistic spectrum share difficulties in the following three areas:

- Social communication (e.g. understanding verbal and non-verbal language)
- Social interaction (e.g. recognising and understanding other people’s feelings)
- Social imagination (e.g. restrictive repetitive patterns of behaviour)

As a spectrum condition, autism affects people in varying ways and requires differing levels of support. Some people with autism are able to live relatively independent lives, but others will need a lifetime of specialist support. Autistic people may have other co-existing conditions, such as a learning disability, or mental health needs. We use the terms “people with autism” and “autistic people” in this Strategy.

Autism can be a “hidden disability”, meaning that it is not always possible to tell that someone has the condition from their outward appearance or behaviour. This makes raising awareness of the condition even more important. People with high-functioning autism may go for many years without a diagnosis, even if they experience less obvious difficulties such as difficulties in social situations throughout their lives.

What have people with autism told us?

The Berkshire Autistic Society (BAS) survey with children, young people and adults with autism, and their families highlighted some important themes and some areas to be addressed to improve support in Reading:

- People wanted more support to increase knowledge and understanding of autism - both for children and adults to know how to manage the condition, and for those who are providing support. Parents especially flagged strategies to manage challenging behaviour as an area where they wanted more training and support.
- Increasing awareness was seen as an important thing to do, especially among those people who come into contact with autistic people in everyday life.
- There was a desire for improved access to information about the support available and what people can expect from different services.
- Parents highlighted the challenge of accessing support when children are not attending school, such as if they've been excluded.
- Many people said there was a need to support carers and families with their health and well-being better, and especially the siblings of autistic children.
- There were strong concerns from carers about the future for the person with autism that they cared for when they are no longer there to provide support.
- Support to ensure that people with autism can succeed in education, employment and training post-16 and into adult life was seen as highly important.
- People felt there should be more accessible leisure opportunities for autistic people to develop their social skills and reduce their isolation.

Some of the feedback given to BAS by people with autism and their carers or family members is quoted throughout the Strategy.

National Context

The 2009 Autism Act and the first national Autism Strategy in 2010 ('Fulfilling and Rewarding Lives') set the national vision for improving the lives of adults with autism. The Department of Health published the updated 'Think Autism' Strategy in 2014, reaffirming the importance of the five areas for action in the original Strategy:

1. Increasing awareness and understanding of autism
2. Developing clear, consistent pathways for the diagnosis of autism
3. Improving access for adults with autism to services and support
4. Helping adults with autism into work
5. Enabling local partners to develop relevant services

The Care Act introduces a wide range of changes to care and support for adults, including a national eligibility criteria and updated rules for assessment and support planning. It gives local authorities a new duty to ensure people can access preventative services and information and advice about care and support. The Care Act gives carers the right to an assessment of their needs in their own right.

While there is no equivalent national strategy for children with autism, there are significant changes to the law for children and young people with special educational needs and disabilities (SEND) through the Children and Families Act. This includes the introduction of single Education Health Care Plans (EHCPs) to replace SEN statements. EHCPs last until a person turns 25 to allow for a more seamless transition between children and adult services. Carers of disabled children also gain similar rights to assessment of their needs as in the Care Act.

The National Institute for Health & Care Excellence (NICE) regularly updates its clinical guidelines that advise on the standards of support for people with autism.

Local Context

One of the aims of this Strategy is to align with existing local plans and strategies across the wide range of areas that cross-over with support for people with autism. Some of the key documents for Reading include:

Health

- Reading's Joint Strategic Needs Assessment
- Reading's Health & Wellbeing Strategy

Children & Young People

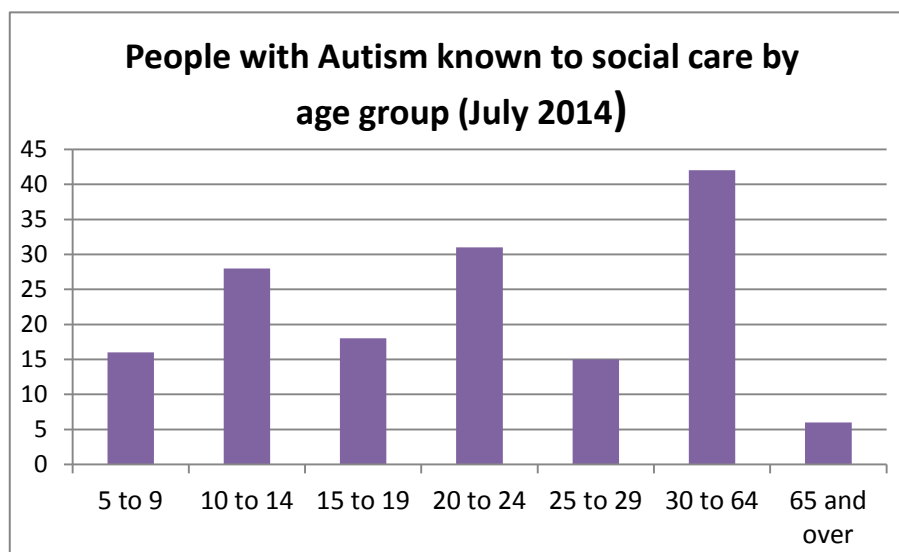
- Reading's Special Education Needs and/or Disability (SEND) Strategy
- Reading's Early Help Strategy

Adults

- Reading's Adult Learning Disability Partnership 'Big Voice' Workplan
- Berkshire West's Joint Commissioning Plan for Services for People with Learning Disabilities and Challenging Behaviour
- Reading's Market Position Statement for Adult Social Care
- Reading's Prevention Framework and Reading's Adult Social Care Information & Advice Plan

Autism in Reading - Local Profile and Needs Analysis

In July 2014, 156 people with autism in Reading were receiving support from the Council's Social Care services. The graph below shows that the numbers are particularly high for children and young people; 62 (40%) of those known to social care are aged 0-19. While this is consistent with the younger than average population in Reading as a whole, it does suggest there may be increasing demand for support in future years as these people grow older.



Of those adults with autism who meet the threshold for social care support, a majority (59%) also had a learning disability. A smaller percentage (6%) of the autistic adults meeting the eligibility criteria also had mental health problems.

The number of people known to social care services only represents a small proportion of the actual number of autistic people. Because many people with autism do not have a diagnosis of their condition or do not meet the threshold for social care support, it is difficult to know how many autistic people live in Reading, and understanding of needs is often based on estimates.

Information on the diagnosis pathway for adults with autism shows high demand, with a waiting time of 28-30 weeks for assessment - an increase on previous years. Of those seen for assessment by the service between April 2013 and March 2014, 46% received a diagnosis of autism and 38% received a partial diagnosis of autistic traits.

The National Autistic Society suggests that 1.1% of the UK population may be on the autistic spectrum or around 700,000 people. In Reading it is estimated that the number of people with autism is slightly higher than the UK ratio, as factors such

as the high number of ICT jobs in the area (a sector that is popular with some autistic people) and the amount of autism support in primary, secondary and tertiary education, mean that autistic people are more likely to choose to live here. With the higher ratio of 1.3%, the number of people with autism in Reading is estimated at 2024 people (using 2011 Census population data) - 1526 adults and 498 children and young people aged 18 and under.

Reading's ethnic diversity has increased by 50% (from 12% to 25%) between the 2001 Census and 2011 Census, so it is now estimated that there are 510 people from black and minority ethnic (BME) groups with autism in Reading, of which 124 are aged 0-18. There is no evidence that autism is more common for different ethnicities, but Reading's diverse population means that the needs of different communities should always be considered when we are looking at providing services and support, and addressing any barriers to accessing these, such as language barriers.

	Adults		Children and young people (0-18)	
Number of people estimated to have autism in Reading	1526		498	
	Female	Male	Female	Male
	381	1145	125	373
	BME	Non-BME	BME	Non-BME
	386	1140	124	374

The Projection of Adult Needs and Service Information (PANSI) suggests an increase of 12.5% in the number of working age adults (aged 18-64) with autism in Reading over the next twenty years, rising to 1219 people by 2030. It is expected this rise will come from the number of children and young people with autism growing older in Reading as well as a number of autistic people drawn to Reading for local jobs and education. This expected future increase means that it is important that there are appropriate services and support in place to meet this need.

Outcomes for people with autism

Education data does give an indication about the experiences of children with autism in Reading schools. In the 2013-14 academic year, 105 pupils in Reading schools had a Statement of Special Educational Needs that identified ASD as the primary need - 19% of all pupils with a statement. Of those pupils who were excluded from school during the first two terms of the academic year (September 2013-April 2014), 19 children had ASD as the primary need on their statement - 20% of all exclusions for pupils with a statement. Absence rates for the first two terms of the 2013-14 academic year at Reading schools are recorded as 5.7% for pupils

with ASD as the primary need. This is higher than the 4.6% absence rate for all pupils, but lower than the 7.6% absence rate for all pupils with statements.

This data suggests that pupils with a statement for autism are more likely to be excluded or absent from school than other pupils, although not more likely than pupils with a statement for other needs. It should be noted that this data only covers those pupils with an autism diagnosis and a statement that identifies this as their primary need, and not those with a lower level of need or without a diagnosis. Parents and carers have raised concerns about children with autism being “unofficially” excluded, although data isn’t available to evidence this.

Current Services and Support for People with Autism

Like all Reading residents, people with autism will come into contact with a wide range of services and organisations throughout their life. It is impossible to list all of these, but some of the main support currently available (either specifically for people with autism, or where autistic people can access help) is explained below:

Children and Young People

Universal support

Services that support all children and young people - **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, as well as with developing strategies to support their child and ensuring that children with autism can access support and opportunities.

Additional support

Berkshire Healthcare NHS Foundation Trust provides a single diagnostic pathway for any child aged 0-18 years through the **Autism Spectrum Disorder Pathway**. The team includes a Community Paediatrician, a Clinical Psychologist and a specialist Speech and Language Therapist. Depending on a child or young person's need, they may be referred for further support from the **Children and Young People's Integrated Therapies (CYPIT)** team - including Speech & Language Therapy, Occupational Therapy, Physiotherapy, and Specialist Dietetics services - or **Children and Adolescent Mental Health Services (CAMHS)**.

Reading Borough Council's **Autism Support Worker** provides support post-diagnosis including a home visit, a free Introduction to Autism Course, and acts as an ongoing point of contact. For families who need additional help, Reading Borough Council's **Children's Action Teams** provide help, guidance and support. The multi-disciplinary teams include Family Workers, Educational Psychologists, Education Welfare Officers, Primary Mental Health Workers and Youth Workers who can help with managing behaviour and children's attendance and attainment at school. Families can also access parenting programmes including the Time Out for Special Needs course through the Parenting Service and that are run by voluntary sector organisations.

Most children with autism in Reading are in mainstream education. Schools can access support from **Educational Psychologists, Speech and Language** and

Occupational Therapy for pupils who need this. Pre-school children including those attending nursery provision with a diagnosis of autism can be supported by the **Portage workers**. In primary schools, two part-time **ASD advisory teachers** give advice on individual children and provide staff training. A massage therapist also works across primary schools in Reading, primarily with children with identified special educational needs including autism.

Adviza provides support to young people aged 13-20 with identified Special Educational Needs to prepare for leaving school. Reading Information, Advice & Support Service for SEND (formerly Parent Partnership) provides confidential, impartial advice and support to parents and carers of children with special educational needs and/or disability, including autism, offering practical help, attending meetings at school and explaining the legal rights.

A range of voluntary groups and organisations support children with autism and their families. **Berkshire Autistic Society** provides post diagnosis support including home visits and training. **Parenting Special Children** provides support pre and post diagnosis including peer support for parents and carers of children recently diagnosed. **Reading Mencap's Family Advisors** also supports families one to one and the **Alpha Service** supports families of children with learning disabilities and autism from BME communities. Reading has a good range of supported activities and short breaks for children. Autism specific activities run by **BAS**, **Children of the Autistic Spectrum Young People's Project (CATSYPP)**, and **Engine Shed** cover different age groups. Some children with autism access activities provided by **Reading Mencap** or **The Avenue School Holiday Play Scheme** for children with learning disabilities.

Specialist support

Reading Borough Council's **Children and Young People's Disability Team** provides assessment and care management to children and young people up to the age of 25 who are eligible for social care support. This can be defined as a level and type of support that cannot be gained from universal services, and where children are at risk of significant harm and statutory processes need to be followed. This includes support in the community such as accessing short breaks provision. Children with complex needs can access overnight and daytime respite at **Cressingham Resource Centre**.

Reading has a range of **specialist education provision** across all school years, including the **Thames Valley School** which currently supports children with a statement of special educational needs where the primary need is autism. There are specialist resource units at **Christ the King Primary School**, **Blessed Hugh**

Farringdon Secondary School and **Reading College** that support pupils with autism alongside the mainstream education provision. Children with autism alongside more complex needs may be supported at **Dingley Nursery** or **Snowflakes Nursery** (0-5 years), or at **The Avenue School** (2-19 years). Some children travel out of the borough to **Brookfields School** in West Berkshire and **Addington School** in Wokingham.

Adults

Universal support

As with children and young people, universal services play a key role for adults with autism. GPs are often the gateway for access to diagnosis services. Organisations such as the emergency services, transport providers, health services such as hospitals, leisure services and other statutory services like the Job Centre must make reasonable adjustments to make sure that autistic people can access and benefit from their services.

Additional support

Berkshire Healthcare Foundation Trust runs an **Autism Spectrum Condition Service** for people suspected of having High Functioning Autism (HFA) or Asperger syndrome. Post-diagnosis, people with autism are offered a 'Being Me' course to understand their condition more. A referral to **Talking Therapies** for a range of therapies, including cognitive behaviour therapy and counselling, may be made if appropriate.

Young people with a learning disability and/or autism can access additional support and specialist courses at further education settings such as **Reading College**. The Council's Adult Education service **New Directions** delivers adult education and provide specialist support for those with learning disabilities, including those with autism. A number of organisations, including **Reading Jobcentre** and **GRAFT Thames Valley** provide support to autistic people to prepare for and find employment. **Royal Mencap** deliver a supported employment service for people with disabilities including autistic people.

There are a number of voluntary and community sector organisations that provide support that prevents people needing more specialist support or that supports them to live as independently as possible in their communities. Some of this support is specific to people with autism. **Berkshire Autistic Society** runs a helpline and information service, and a range of social clubs. BAS also offers an

Autism Alert card to people with a diagnosis that can be shown to explain the condition. **Reading Mencap** provides a number of clubs and regular activities for adults with learning disabilities (including those with autism). Other voluntary groups provide social clubs and events that support people on the autistic spectrum, including **Berkshire PHAB**.

People with autism involved with the criminal justice system can access the **Liaison and Diversion Support Worker** who supports vulnerable offenders.

Specialist support

Reading Borough Council provides assessment and care management to people with autism who meet the Adult Social Care eligibility criteria. Depending on a person's age, the **Children and Young People's Disability Team (0-25)** or the **Adult Disability Team (25+)** provides or arranges support that aims to help them to lead safe and fulfilling lives, with a focus on promoting independence and giving choice and control to service users, through access to Personal Budgets. The support can take many forms and may be from an organisation that specialises in supporting autistic people.

Berkshire Healthcare NHS Foundation Trust runs the **Community Team for People with Learning Disabilities** which provides specialist health services for people with learning disabilities, including some people with an autism diagnosis. The team has community nurses, occupational therapists, physiotherapists, psychologists, psychiatrists and speech and language therapists. Where people with autism present with complex and challenging behaviours, the teams work closely with assessment and treatment centres to support and reduce the impacts of such behaviours on people's ability to lead independent and safe lives.

Reading's **Community Mental Health team** is a partnership between Berkshire Healthcare Foundation Trust and Reading Borough Council to provide support. The team provides no autism-specific services, but a number of service users have autism alongside mental health needs.

Priority 1 - Increasing Awareness and Understanding of Autism

Widening awareness and knowledge of autism

Berkshire Autistic Society's research highlighted the importance of raising awareness of autism as much as possible among everyone who has contact with people with autism in a professional capacity. Understanding among GPs is critical as they are often the gateway to diagnosis. Increasing access to training and ensuring that existing training is accessed by the right people and across a broad range of organisations and services is key to widening awareness. Autistic people and their families should be involved in planning and delivering this training as much as possible. Taking opportunities to raise public awareness of autism through local events and information sources is also important.

People with significant contact with people with autism such as teachers, social care and health staff should be supported to deepen their understanding of autism. This should include building confidence to respond to autistic traits and behaviour and provide appropriate support, even before or without a diagnosis. Specific training may also be needed for those who support young autistic people transitioning to adult services, or for those supporting older people with autism.

- Review existing training across different organisations and identify gaps
- Develop a training programme with the involvement of people with autism with options such as online training
- Encourage organisations to access autism awareness training for their staff
- Support staff across health and social care teams to develop knowledge through accessing specialist training and sharing with others
- Work with education settings to develop understanding of autism and the confidence to respond to the behaviour of pupils with autistic traits

Helping people to access information, advice and support

The research by BAS found that people felt they did not always know what they could expect from various services, or find clear information in one place. The Council will continue to develop its information and advice offer to support people. A key element of this is the Reading Services Guide that is accessible online and through other methods

"The Autism Support Worker was great. Other support was good, but I found it difficult knowing where to look for support."

Parent of a child with autism

such as by phone or with the support of a professional/volunteer. This will be supported by other methods of providing information, advice and guidance, including working with groups who are trusted or already have a relationship with people to provide effective and timely information.

- Continue to develop information and advice offered so that people with autism, families and carers can access clear, accurate and timely information in a range of ways
- Promote autism awareness through the Reading Services Guide

Supporting autistic people and their families/carers to understand autism

People diagnosed with autism and their families stressed the importance of training and education that supports them to explain and manage behaviour, and to develop communication and social skills. For parents of children with challenging behaviour, this could include support with strategies to manage behaviour from school staff or the Children's Action Teams. This support needs to be adapted to ensure that it meet the needs of different people, such as those with limited literary or English skills. The Council will continue to work with partners in the voluntary and community sector to ensure that support reaches different parts of the community, such as those from different BME groups.

- Work across partners to ensure people with autism and their carers are supported to access training and support to manage their condition, including different BME groups

Priority 2 - Improving Access to Diagnosis & Beyond

Autism diagnosis services

"I was first mistaken for having a learning disability for 11 years, and misdiagnosed with a borderline personality disorder from 1999."

Adult with autism

Raising awareness of autism is especially important for getting a diagnosis of autism, as universal services such as schools and GPs are often the starting point for someone to discuss concerns. Helping people to understand autism and access services for assessment can be particularly important for adults who may have never had a formal diagnosis. Not everyone will want a diagnosis, but for some it is important to be able to understand their condition and explain their behaviour to others.

Reading has diagnosis pathways in place for children and young people and, separately, for adults. There are currently waiting lists for both services. In the research completed by BAS, 58% of parents said it was hard to get their child diagnosed, with the most common reason being the wait for an appointment. Diagnosis services are the responsibilities of the Clinical Commissioning Groups. Reviews of the current pathways are needed to ensure that capacity is available to see people within the timescales recommended by the National Institute for Health and Care Excellence (NICE) clinical guidelines.

- Work with health services to review the effectiveness and capacity of the children's and adult's diagnosis pathways
- Establish processes to signpost adults awaiting diagnosis to available support

Support after diagnosis services

After a diagnosis of autism, children and young people can access support from a range of places, depending on the level of need identified. Parents responding to the BAS survey were especially positive about the support of the Council's Autism Support Worker and liked the idea of someone to co-ordinate their child's ongoing support from across services. In the future this co-ordination will take place for any child eligible for one of the new Education, Health and Social Care Plans (EHCPs) through this process. A possible gap in existing post-diagnosis support is for young people who receive a diagnosis, who could benefit from support specifically developed for their age range.

Adults who have received a diagnosis are offered a range of additional support including courses provided by voluntary organisations, and access to further health services such as Talking Therapies as appropriate to their individual situation. The research by BAS does note that this can only support a small number of those diagnosed, particularly as the number of adults being referred and diagnosed continues to increase. There is more work to do to ensure there is sufficient post-diagnosis guidance and support for people, including those who do not receive a diagnosis and may need to access provision such as Talking Therapies.

- **Align with work through the Special Educational Needs & Disability Strategy to better co-ordinate support for children with autism**
- **Work with partners to ensure that people receiving a diagnosis can access appropriate support such as training, peer support, and resources to support self-management**

Priority 3 - Supporting Better Life Outcomes for People with Autism

Education

Reading's Special Educational Needs and Disability (SEND) Strategy sets out how the Council will meet the requirements in the Children & Families Act, including the move to single Education Health Care Plans (EHCPs) to replace SEN statements. Work is underway to review all pupils who currently have SEN statements and, if appropriate, transfer these to EHCPs by 2017. EHCPs cover provision 0-25, to support improved transitions, and include all partners in an integrated process. The child or young person and their family are an essential part of this, to ensure the plan is personal to meet the individual needs identified.

"Previous schools have not taken his needs into consideration and my son was left unsupported, behind in his work, with no friends."

Parent of a child with autism

"School has been amazing, putting immediate interventions into place."

Parent of a child with autism

Many parents stressed the importance of getting the right support for their autistic children in school. The Council will continue to work in partnership with schools (both mainstream and specialist) to improve outcomes for pupils with autism, supporting their learning and attainment, and their development of social and communication skills. Using routes such as the Pre-School SENCO network supported by the Educational Psychologists to share learning and build knowledge that can be taken back to settings are important ways that this can be further developed. Pupils who have low attendance or are excluded are currently a particular area of focus, and Reading Borough Council's School Improvement Service is focusing on addressing issues for pupils with SEN (including those with autism identified as a need) through a number of measures to support and challenge schools and settings. Another opportunity is to facilitate support offered between schools, particularly from those with more specialist expertise.

- Align with work to deliver the SEND Strategy to improve support for pupils with autism, including those move to Education, Health & Care Plans
- Continue to work with schools to strengthen knowledge and skills to support pupils with autism, encouraging links between specialist and mainstream settings
- Support the Virtual Head for CME (Children Missing Education) to work

with schools to reduce exclusions and low attendance among children with autism

Training and Employment

"I have not worked due to inaccessibility in employee selection during a job interview in 1985-86"

Adult with

Moving on to further education, training or work is an important time for people with autism. While there are a number of options available in Reading, person-centred support is important to help young people to find the right opportunity. Local employment support organisations already help people with autism with taking steps towards employment, and the Elevate Reading project offers an opportunity to strengthen the support available in an integrated way. The Elevate Reading project will introduce a co-located central hub for employment support for 16-24 years - including traditional services such as Jobcentre Plus and wider support such as mentoring schemes run by the voluntary sector. The Hub will bring together organisations that work with employers to increase job opportunities, including for people with autism. The Council's newly commissioned supported employment service for people with disabilities will be based at the hub, to enable it to specifically support people with autism to find and retain employment in partnership with other local organisations.

- Establish the supported employment service for people with disabilities including autism to help people find work that is appropriate for their skills
- Work with partners in the Elevate Reading project to increase awareness among employers about autism and to increase opportunities for people with autism to experience, find and retain work

Health, Social and Leisure

Ensuring people with autism can access universal services should be the starting point to support people in Reading's communities to stay healthy, live fulfilling lives and develop social skills. The Council will continue to work with a range of local services such as leisure facilities to support them to make reasonable adjustments that enable autistic people to access their services. Specific activities for children, young people and adults with autism are also important, and the Council works with a mix of voluntary organisations to offer a range of social and

leisure opportunities, including support groups. The Council's Early Help Strategy (for children, young people and families) and Prevention Framework (for adults and carers) both confirm the commitment to provide low-level, community-based services - particularly for those who are not eligible for social care services and often rely on these services for support and advice. People have suggested areas for development such as peer support groups and buddying at transitions e.g. when leaving school; the opportunities to introduce these will need to be explored within existing funding.

- Support a wide range of organisations to develop autism awareness, to ensure people with autism are confident to access their services
- Work with partners including voluntary and community sector groups to explore ways to further develop local autism community support

For people with autism where their needs are more complex, health and social care staff will continue to support them to develop skills to live as independently as possible. Those people who are eligible for support from health and social care teams are helped by staff to feel confident and comfortable about accessing health services such as health screenings and reviews. More widely, there is work that partners including health services and the Council's Public Health team can do to ensure that all autistic people are supported to stay healthy, e.g. attending GP health checks. Parents were concerned about access to health support for their child with autism, particularly the waiting times and lack of clear pathways for some specialist services. The establishment of the Children and Young People's Integrated Therapies (CYPIT) with a single referral route aims to address some of these issues.

"Larger swimming groups with teachers who do not understand ASD was not a good experience"

Parent of a child with autism

- Work across partners to ensure that people with autism are supported to access services that help their health and wellbeing
- Gather feedback on the effectiveness of the new Children and Young People's Integrated Therapies (CYPIT) to support plans to shape the future service

Priority 4 - Supporting People with Autism to Live Safely and as Independently as Possible

Transitions to adult services

Moving from children's to adult's service can be a challenging time for young autistic people and their families. Schools, colleges and other education providers have a critical role to ensure that young people can access the right support at this point in their lives. Voluntary sector organisations and peer support opportunities can also be important support to people through this period.

- **Align with work for the SEND Strategy to review pathways for transitions between children and adult services**

Housing

As adults, the level of support that people with autism need will vary greatly. Promoting independence is a key principle in Reading, and all services will aim to help people to live as independently as possible for their own level of need. There are a range of housing options available to people on the autistic spectrum, from living alone or with a family, to supported living and residential accommodation. Reading Borough Council's recent tender for a Supported Living Accreditation Select List (SLASL) aims to ensure that high quality and good value Supported Living is available for all people who need this type of accommodation. The aim is that the providers on the list can develop their specialist knowledge so their provision can meet the range of needs in Reading, including people with autism. However, there will still be an option to have some level of specialist provision if someone with autism (for example) has very specific needs that cannot be met by any of the providers.

For those people with autism and challenging behaviour who need very specialist support, Reading Borough Council is working with neighbouring authorities and health partners on the Berkshire West Joint Commissioning Plan for Services for People with Learning Disabilities, Autism and Challenging Behaviour. The Plan has developed in response to the Winterbourne Review and aims to ensure that people with challenging behaviour are supported to remain living in their local communities and that any in-patient assessment and treatment is timely and, where possible, provided locally. Where people are placed out of Berkshire they are regularly reviewed and moved back to Berkshire where appropriate. Working together across Berkshire and across organisations will be critical to ensure that very specialist support is available to those that need this.

- Support providers on the Supported Living Accreditation Select List develop their skills and expertise to support people with autism
- Work with the Council's Housing team and local housing providers to ensure there is a range of accommodation for people with autism
- Work with partners across Berkshire West to improve support for people with autism and challenging behaviour

Staying safe and independent

"I don't have any help meeting appropriate people safely. There is a lack of opportunity to make genuine friends."
Adult with autism

Adults with autism need to feel confident and safe in their communities. The research completed by BAS found that autistic people are more likely to be at risk of financial abuse and other forms of abuse such as 'mate crime'. Advice and support should be accessible to adults with autism where needed to help them to live independently - managing money or staying safe online, for example. We will continue to work with agencies such as Jobcentre Plus to support people to access universal services, and offer travel training for children, young people and adults with autism to help people feel confident to get around independently. Other tools that provide practical support to help people with autism to live safely, such as the Berkshire Autistic Society's Autism Alert Card, will also continue to be supported. Autistic people are more likely to come into contact with the criminal justice system, and these services should be linked to other support available across partners to ensure that vulnerable defendants are supported pre-sentencing, including access to diagnosis if this is identified as a need. As adults with autism get older there may be a need for further support, if carers develop their own support needs, or to address additional health problems such as dementia. The Council will work to ensure that its team and other organisations supporting older people can understand and be aware of the potential impact of autism on the people they work with.

- Work with partners in the criminal justice system to raise awareness of autism and ensure that people with autism are supported appropriately
- Promote and support local initiatives that help people with autism to feel safe in their communities
- Ensure that services and organisations working with older people are aware how people with autism may need further support

Priority 5 - Supporting Families and Carers of People with Autism

Parents, families and other carers often provide valuable ongoing support to autistic people, both as children and through adulthood. The demand on carers will vary depending on the individual needs of the person being cared for, but in Berkshire Autistic Society's Survey of Carers in 2013, 33% of carers said that they never get a break from caring, and 50% reported suffering from depression and physical problems such as difficulty sleeping.

The Care Act introduces new rights for carers of adults, so that they are entitled to an assessment of their needs and support if they are eligible. Adult carers of disabled children get similar rights from the Children and Families Act. Not everyone will provide a level of support that will mean they qualify for support funded by the Council, but the assessment can also identify other types of support available in the local area that carers might benefit from. The Council is using the changes to the law to refresh its existing offer to carers and to make sure more carers are aware of their role and the support available to them. Locally we are choosing to support adult carers in the same way, whether they care for a child with a disability or an adult.

"I feel that while I am living I can continue to protect my daughter's interests, but I worry about the time when I shall not be around"

Parent of an adult with autism

A gap identified by BAS in their research was support for siblings of children diagnosed with autism; as part of our whole-family approach, we will make sure that siblings are referred to services for young carers and know about other opportunities that will support them. Opportunities for short breaks were highly popular with parents, and a review of current provision is under way currently.

- **Align with the work to implement the Care Act and the Children and Families Act to make sure carers of autism are aware of their rights and offered an assessment and further support (depending on their needs)**
- **Work with partners to promote the support available to carers and families of people with autism**
- **Review existing short breaks provision for children with autism**

Priority 6 - Improving how we Plan and Manage Support

Collecting and using data

There is limited data available on autism, with planning based mostly on estimated data and on the small percentage of people with autism known to Social Care services. We will work with partners to look at how data could be better collected about levels of autism locally and the outcomes for autistic people, to support further work and identify areas for development. While projections show that the number of people with diagnosis is increasing, improved use of data on local diagnosis rates would help local services to ensure that there is sufficient capacity to meet increasing demand and to inform the development of education provision, for example. This should be addressed in future policies and plans across different services and organisations, such as the Joint Strategic Needs Assessment.

- **Work across partners to improve data collection about people with autism, and the use of this to inform service planning**
- **Ensure that the needs of people with autism are included in plans and policies for developing services**
- **Work with the Public Health team to explain the needs of people with autism (including any specific issues for different genders, ethnicities and age groups) in the Joint Strategic Needs Assessment**

Providing support across the spectrum

Previously, young autistic people transitioning to Adult Social Care services were assessed and, if eligible, moved to the Learning Disability or the Long-Term Support teams. The Council's reorganisation into a life-long Disability service aims to address this split for those who are eligible for ongoing support. We will continue to monitor the effectiveness of this rearranged service to meet the needs of adults with autism. While a number of adults with autism are eligible for Social Care services, many others across the spectrum live independently or with family support. We are committed to working with partners to provide appropriate support at all levels, from signposting and support groups up to specialist support to people with autism.

- **Work together across partners to ensure people with autism can access appropriate support, including those who do not meet the eligibility threshold for social care services**

Overseeing support and involvement

More detail about how the Strategy will be overseen with the input of a range of partners is set out in 'Delivering the Strategy' below. These partners will support the work to involve and engage autistic people and their families and carers in the delivery of the Strategy and the shaping of services, building on the work so far to ensure that the Strategy is built on the views of people who use services that support people with autism already.

- **Continue to work to involve people with autism, their families and carers in delivering the Strategy and shaping future services**

Delivering the Strategy

Developing the Autism Partnership Board

The production of this Autism Strategy has been underpinned by the Berkshire Autistic Society research, and particularly by their consultation with people with autism and their families and carers to inform our future plans. BAS set up a Steering Group with representative from key agencies and organisations. The Autism Strategy Steering Group (with a refreshed membership) has continued meeting to drive the development of the Autism Strategy and to make sure that it is focused on the needs of autistic people and their families and carers in Reading.

The Group will continue meeting quarterly once the Strategy is published, as an Autism Partnership Board. Terms of Reference set out its role to oversee the delivery of the Strategy through an Action Plan and to support a wide range of organisations to improve their awareness of autism and “think autism” in their delivery and development of services. The Board will continue to focus on partnership working with members from social care, education and health services, other organisations across the statutory and voluntary and community sectors, and people with autism and their families and carers.

Autism Strategy Action Plan

Delivery of the Strategy will be supported by the development of an Action Plan by the Partnership Board to set out in more detail how the work will be progressed. This might involve setting up sub-groups to do more detailed work, or involving different services and organisations as appropriate.

The Partnership Board will report back on progress with the delivery of the Autism Strategy to Reading’s Health & Wellbeing Board and to Reading’s Learning Disability Partnership Board. The Strategy and the Action Plan will support the completion of the Autism Self-Assessment (for adults with autism). It will demonstrate how it is narrowing the gap for people in Reading, in line with the Council’s ambitions in the Corporate Plan 2015-18, and improving outcomes for children, young people and adults with autism, their carers and families.

Improving Outcomes for People with Autism

Delivery of the Strategy and the Action Plan should enable Reading to meet its aim of improving outcomes for children, young people and adults with autism, and their families and carers. Achieving the actions set out in this Strategy should support changes for people so that we can show that we meet the following outcomes:

Adults with autism

- People with autism achieve better health outcomes
- People with autism are included and are economically active
- People with autism are living in accommodation that meets their needs
- People with autism are benefitting from the personalisation agenda in health and social care and can access personal budgets
- Adults with autism are no longer managed inappropriately in the criminal justice system
- People with autism, their families and carers are satisfied with local services
- People with autism are involved in service planning

Children and young people with autism

- Better educational outcomes - narrowing the gap in attainment, ensuring good attendance and reducing exclusions (linked to the objectives of Reading's Special Educational Needs & Disabilities Strategy)
- Being safer - improving parenting skills and confidence to manage behaviour related to autism
- Being included and able to participate
- Improving access to universal services and use of these services
- Improving access to and use of information and advice
- Being independent - reducing the number of young people not in education, employment or training