

# Needs Assessment for Autistic Children, Young People & Adults Reading



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# Glossary and Abbreviations

## Abbreviations

<b>AET</b>	Autism Education Trust
<b>ASC</b>	Autistic Spectrum Conditions
<b>ASD</b>	Autistic Spectrum Disorder
<b>ARFID</b>	Avoidant/restrictive food intake disorder
<b>BfC</b>	Brighter Futures for Children
<b>BOB ICS</b>	Berkshire West, Oxfordshire and Buckinghamshire Integrated Care System
<b>CAMHS</b>	Child and Adolescent Mental Health Services
<b>CCC</b>	Cambridgeshire County Council
<b>CCG</b>	Clinical Commissioning Group
<b>CYP</b>	Children and Young People
<b>CYPIT</b>	Children and Young People's Integrated Therapies
<b>CiN</b>	Child in Need
<b>CJS</b>	Criminal Justice System
<b>CQC</b>	The Care Quality Commission
<b>GP</b>	General Practitioner
<b>EHA</b>	Early Help Assessment
<b>EHCP</b>	Educational Health and Care Plan
<b>HNA</b>	Health Needs Assessment
<b>ICD</b>	International Classification of Diseases
<b>ICP</b>	Integrated Care Partnership
<b>ICS</b>	Integrated Care System
<b>IQ</b>	Intelligence Quotient
<b>JSNA</b>	Joint Strategic Needs Assessment
<b>L&amp;D</b>	Liaison & Diversion
<b>LA</b>	Local Authority
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NHS</b>	National Health Service
<b>MDT</b>	multidisciplinary team
<b>RBC</b>	Reading Borough Council
<b>OT</b>	Occupational Therapist
<b>PANSI</b>	Projecting Adult Needs and Services Information
<b>PSC</b>	Parenting Special Children
<b>PHOF</b>	Public Health Outcomes Frames
<b>POPPI</b>	Projecting Older People Population Information
<b>QOF</b>	Quality and Outcomes Framework
<b>SALT</b>	Speech and Language Therapists
<b>SHaRON</b>	Support, Hope and Resources Online
<b>SEND</b>	Special Educational Needs and Disability
<b>SENCO</b>	special educational needs coordinators
<b>SLC</b>	Speech, Language and Communication
<b>STR</b>	Support Time Recovery workers
<b>UK</b>	United Kingdom

## Glossary

<b>Asperger syndrome</b>	Refers to a group of autistic people who have average or above average intelligence, have fewer problems with speech than many others with autism and who do not have a learning disability but may have specific learning difficulties (National Autistic Society, 2016). There is not a clear boundary between Asperger syndrome and other kinds of autism. The diagnosis is no longer in current use and autism is regarded as a spectrum condition encompassing many different forms, including forms of autism that may have previously been diagnosed as Asperger Syndrome (WHO, ICD-11, 2020; American Psychiatric Association, DSM-V, 2013). Although no longer in current use many people continue to use and identify with the term.
<b>Autism Spectrum Disorder (ASD)</b>	This is the term used in the most up to date version of the International Classification of Diseases (ICD-11). It is used to refer to a range of conditions meeting the criteria for autism (see 'Autism' below) (WHO, ICD-11, 2022; American Psychiatric Association, DSM-V, 2013). Although still in use as a clinical diagnosis, some consider the use of the word 'disorder' reinforces the view of autism as a deficit, rather than a difference.
<b>Autism Spectrum Conditions (ASC)</b>	Used by some as an alternative to ASD due to some considering ASC the appropriate language to refer to an autistic person over the life course, reflecting the fact that they will have autism throughout life but varied experiences and impacts at certain times and in varied ways, therefore eliminating any perceived stigmatisation and promotes their individual strengths. ASC is a more positive term showing autism as a difference not a defect.
<b>Autism</b>	Refers to a spectrum condition which encompasses a range of characteristics that typically include challenges with social interaction and communication, repetitive or inflexible patterns of behaviour or interests, and feelings of discomfort, anxiety or distress in certain environments (such as where there are loud noises or bright or flashing lights) (NHS, 2022)
<b>Care pathway</b>	The UK National Institute for Care and Health Excellence (NICE) uses the term 'care pathway' to refer to a standardised process for providing care that is based on the best evidence available and aimed at promoting the most efficient care and optimising outcomes for service users (NICE, 2016)
<b>Education, Health and Care Plans (EHCP)</b>	A legal document outlining a child or young person's special educational, health and social care needs and what additional help and support is required in school beyond that which schools can provide, to meet those needs. (Contact 2012). Formerly known as Statements of Special Needs.
<b>Graduated Response</b>	The graduated response is a 4-stage cycle that helps to provide a growing understanding of a child or young person's strengths and needs and what helps them to make good progress and have good outcomes. As the level of the child or young person's need increases, so this cycle, and their support become more targeted. Includes 4 parts – Assess, Plan, Do, Review. (SEND Code of Practice [2015])
<b>Learning Disability</b>	A learning disability is having intellectual abilities that result in a person experiencing difficulties with everyday activities which affects someone for their whole life (Mencap 2018) and is usually defined as having an IQ of less than 70. A learning disability can range from mild, perhaps meaning a person will need support in gaining employment but be otherwise independent, through to profound and multiple learning disability (PMLD) where a person has multiple disabilities, the most significant of which is a learning disability and will need a carer or carers to help them with most aspects of daily life, such as washing, eating and using the bathroom (NHS Choices 2015). Some autistic people also have a learning disability, but autism itself is not a learning disability.
<b>Learning Difficulty</b>	Learning difficulties affect the way information is learnt and processed. There are several levels of Learning Difficulties, such as: <ul style="list-style-type: none"> <li>• <b>Specific Learning Difficulty (SpLD)</b> - a particular difficulty in learning to read, write, spell including dyslexia, dyscalculia, dyspraxia and attention hyperactivity deficit disorder (ADHD).</li> <li>• <b>Moderate Learning Difficulty</b> - achievements well below expected levels in all or most areas of the curriculum, despite appropriate interventions</li> <li>• <b>Severe Learning Difficulty</b> - significant intellectual or cognitive impairments</li> <li>• <b>Profound and Multiple Learning Difficulty</b> - multiple Learning Difficulties have severe and complex learning needs, in addition they have other significant difficulties, such as physical disabilities or a sensory impairment.</li> </ul> Learning difficulties can occur alongside autism. (British Dyslexia Association 2018).
<b>Local Offer</b>	A resource that gives children and young people aged 0 - 25 years with special educational needs and/or disabilities and their families (including parents, carers) information about what support and services are available in the local area and understand how to access them. It is a statutory requirement for local authorities to publish their local offer.
<b>Short Breaks</b>	Short breaks provide opportunities for disabled children and young people to spend time away from their families and have fun, take part in new experiences and learn new skills. They also provide families with a break from their caring responsibilities. The Breaks for Carers of Disabled Children Regulations 2011 requires local authorities to provide a range of short breaks for families with disabled children (age 0-19yrs).
<b>Special Educational Needs (SEN)</b>	"A learning difficulty or disability which calls for special education provision to be made" (Children and Families Act 2014). Special educational needs and disabilities (SEND) can affect a child or young person's ability to learn; their behaviour or ability to socialise, e.g., they may struggle to make friends; reading and writing, for example because they have dyslexia; ability to understand things; concentration levels, for example because they have ADHD; or physical ability (HM Government 2018).
<b>The Care Act 2014</b>	The Care Act aims to ensure the wellbeing of people in need of care and support services. It also aims to bring about the personalisation of care services, putting the person at the centre of the process.
<b>The Equality Act</b>	The Equality Act 2010 legally protects people from discrimination, harassment and victimisation in the workplace and in wider society. It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone. (gov.uk)
<b>Ordinarily Available Provision</b>	Refers to the baseline common set of expectations of support that mainstream schools or settings should be able to provide for a child or young person aged 0 to 25, through their agreed funding and resource arrangements for the majority of children with SEN, within settings, schools and colleges.

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## **Task and Finish Groups**

### **Forums and Engagement Task & Finish Group and Needs Assessment Task & Finish Group**

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## **A keynote of terminology/language used**

The report is structured as is typical for a Needs Assessment in Public Health. It is acknowledged that different people have different views on terminology relating to autism. 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 such as the term 'people with autism', 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 assessment is intended to be inclusive to all those identifying with any of these terms, or related terms.

## Brief Executive Summary

This is a short summary of Reading's Autism Needs Assessment. You will find more detail on these key points in the full Executive Summary and for full information please see the main report.

## Risk factors and inequalities



No one knows why some people are autistic and there are no clear patterns to tell us whether there are likely to be more autistic people in some groups or populations than others. Although more males are autistic than females this is now thought to be the result of under-diagnosis in women and girls. Access to assessment and diagnosis is likely to affect how many people are known to be autistic and this may be different in different socioeconomic and ethnic groups.

## How many autistic people live in Reading?

An estimated **1,707** people in Reading are autistic, including **353** school aged children. This is based on a national estimate, so the true local number could be larger or smaller. There is a lot of uncertainty about how to estimate the number of autistic people in a population, so it is difficult to be definite about this.



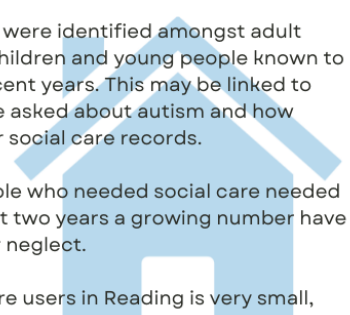
Data from primary care showed **489 adults** and **644 children** who lived in Reading had a diagnosis of autism recorded by their GP, suggesting more children in Reading are diagnosed with autism than average, but fewer adults. This might be because of the way in which people access assessment or for other reasons.

## Social care and housing

Only a small number of autistic adults were identified amongst adult social care users and the number of children and young people known to social care has been decreasing in recent years. This may be linked to whether and how social care users are asked about autism and how someone's autism is recorded on their social care records.

Most autistic children and young people who needed social care needed support with a disability, but in the last two years a growing number have received support because of abuse or neglect.

The number of autistic adult social care users in Reading is very small, especially amongst those aged over 65 years. A small number of adult social care users diagnosed with autism in Reading are entitled to S1117 aftercare and were provided with a direct payment, residential care or a supported living placement. Most had a primary or additional diagnosis of a learning disability, mental health condition or both.



## How do autistic people in Reading get diagnosed with autism?

In Reading, being assessed for autism is often a long and complicated process. Waiting times for children can be up to two years and children sometimes need to attend lots of separate appointments with different professionals.

Although our needs assessment showed there was a range of support for people while they are waiting to be diagnosed, many autistic people and their families reported not feeling well supported.

## Specialist care and support for autistic people in Reading

Social care support is available from Brighter Futures for Children and Reading Borough Council's Adult Social Care for people who have care needs. In addition, a range of different support is available from voluntary sector and peer support groups for those with and without care needs.

More information sharing and clarity about what services are available may help to improve access to specialist care and support for autistic people.



## Education

There are more autistic children in Reading than might be expected based on national prevalence estimates and prevalence of autism in children and young people in Reading is increasing over time. Schools should anticipate that at least a small number of children in each school will be autistic and plan to respond to their needs.

Families in Reading had good awareness of the online 'local offer' and permanent exclusions were generally low. However, many parents and carers felt strongly that autism was sometimes misunderstood as poor behaviour and felt that awareness of autism could be improved. The Reading Autism Education Trust (AET) hub has recently been established and is designed to raise awareness of autism, help to ensure schools adopt high standards for supporting autistic children and young people and facilitate a culture change in these settings.

More support may be needed to make sure that young people with SEND and autistic young people in Reading are able to get support to access further and higher education, training and employment.

## Training and employment

Nationally, only around 10-15% of autistic adults are in employment. Most autistic people want to work and are able to work, but may require adjustments and awareness by employers or support to make the transition from education or training into employment.

Focus groups with autistic adults in Reading highlighted the lasting impact of bullying and poor experiences in education on self-esteem and self-belief and the challenges of social interaction with colleagues and in the workplace.



## Criminal Justice System

Little information is collected about autism in local criminal justice settings, but nationally there is evidence that autistic people are over-represented in the criminal justice system.

Thames Valley Police have identified a lack of awareness of autism and have begun to train officers and to use an 'Autism Alert Card' to help identify autistic people who are taken into custody. Liaison and diversion services provide assessment, diagnosis and referral of vulnerable people in criminal justice settings to appropriate support services.

Respondents have reported a lack of services to support autistic adults in the criminal justice system and suggested that more joined-up, cross-agency working may be needed.

## Parents and carers of autistic people

Parents and carers of autistic children in Reading told us that accessing assessment for autism was difficult and challenging and that they had to wait a long time. Many felt that they did not have enough contact and communication during the process and found this stressful and worrying.

Although many parents and carers reported positive experiences of services, most also reported poor post-diagnosis support. Only a very small number of carers of autistic adults provided feedback for this needs assessment.



## Transport

According to the UK National Autism Strategy, transport is a key enabler in helping autistic people become active members of society.

Reading's Transport Strategy takes an autism-inclusive approach. Reading Buses and Brighter Futures for Children School Transport use drivers trained about the needs of autistic people.

Many autistic people find public transport noisy, crowded and uncomfortable. We have little information about autistic people's use of public transport in Reading, including children and young people who use school transport.





## 2 | Introduction

### 2.1 What is autism?

Autism is a lifelong developmental condition that affects the way that a person interacts with and experiences the world around them and how people perceive, communicate and interact with others.<sup>1</sup>

The NHS<sup>2</sup> notes that different terminology is commonly used to describe autism, including autism spectrum disorder (ASD); autism spectrum condition (ASC) and Asperger's (or Asperger syndrome). The NHS also recognises that autism is not a medical condition, with treatments or a "cure", but rather a difference in brain functioning.

Autism is not a learning disability, but some reports suggest that around 60-70% of autistic people have a learning disability<sup>3</sup> compared to 2.16% of neurotypical adult people<sup>4 5</sup>. **Estimates vary and true prevalence of learning disability amongst autistic people is unclear.** As we understand more about autism and its impact on people, the definition of autism could evolve further in future.

Autistic UK<sup>6</sup> report 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 'pathologised'.

Reading strongly advocates for the importance of neurodiversity, describing autism as a difference and not a deficit, and seeking to maximise the opportunities for neurodiverse children and young people.<sup>7 8</sup>

#### 2.1.1 How does autism present?

Autistic people see, hear and feel the world differently to other people. 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. Some autistic people can live independent lives, but others may face additional challenges and require life-long care and support.

Common challenges experienced by autistic people, with some examples, 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/hobbies (when this leads 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)<sup>1</sup>

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

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

<sup>3</sup> 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>.

<sup>4</sup> Foundation for People with Learning Disabilities (2016). Learning disability statistics: autism. [online] Available at: <https://www.learningdisabilities.org.uk/learning-disabilities/help-information/statistics/learning-disability-statistics-/187690>.

<sup>5</sup> Public Health England (2016). Learning Disabilities Observatory. People with learning disabilities in England 2015: Main report.

<sup>6</sup> Autism UK (2020). Neurodiversity. [online] Available at: <https://autisticuk.org/neurodiversity/> [Accessed Dec. 2021].

<sup>7</sup> 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/>

<sup>8</sup> 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>.

The causes of autism, if they do exist, are still unknown. People are born with autism and it is common for signs of autism to present themselves from a very young age. Contrary to some beliefs, autism does not result from diet, bad parenting or vaccines.

Autistic people often have co-occurring conditions, including dyslexia, dyspraxia, epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD) as well as behaviours such as difficulty sleeping and self-harm. NICE guidelines<sup>8</sup> note that the frequency of co-occurring conditions, such as ADHD and LD means that 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 (intellectual) disability (intelligence quotient [IQ] below 70) occurs in approximately 50% of *young* autistic people (NICE, CG128, 2011<sup>8</sup>) (a different figure for estimated prevalence of learning disability amongst autistic adults is reported elsewhere).

Caring and supporting an autistic person can be demanding but also rewarding. The demands on families providing ongoing care and support, in particular, 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. Autism often has an impact on education and employment opportunities. Autistic people are often subject to stigma, discrimination and human rights violations (WHO<sup>9</sup>).

### 2.1.2 Support needs

Not all autistic people will need care or support and 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.<sup>10</sup>

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<sup>11</sup>

### 2.1.3 Population

There are an estimated 700,000 autistic adults and children in the UK – approximately 1% of the population. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (National Autistic Society<sup>1</sup>). Autism was once considered to be an uncommon developmental disorder; however, recent studies have reported increased prevalence.<sup>8</sup>

### 2.1.4 Autism over the life course

#### *Under 19 years*

Evidence suggests that both genetics and environment and the interplay between them, likely play a role in the development and evolution of autism<sup>12</sup>. Further research is needed in this complex area.

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<sup>9</sup> WHO (2017). Autism Spectrum Disorders. Available at: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>.

<sup>10</sup> National Autistic Society. Available at: [Varying support needs \(autism.org.uk\)](https://www.autism.org.uk/support-needs)

<sup>11</sup> National Autistic Society. Available at: [Adults \(autism.org.uk\)](https://www.autism.org.uk/adults)

<sup>12</sup> National Institute of Neurological Disorders and Stroke (NINDS) (2019). Autism Spectrum Disorder Information Page. [online] Available at: <https://www.ninds.nih.gov/Disorders/All-Disorders/Autism-Spectrum-Disorder-Information-Page>.

The core autism behaviours are typically present in early childhood, but features are not always apparent until the circumstances of the child or young person change, for example when the child goes to nursery or primary school or moves to secondary school. In some cases, autism may not be diagnosed until much later in life.

When autism is diagnosed, families and carers and the child or young person themselves can experience a variety of emotions, shock and concern about the implications for the future. Some may also have a profound sense of relief that others agree with their observations and concerns.

According to NICE guidance, autistic children and young people should have full access to health and social care services, co-ordinated and managed through local specialist community-based multidisciplinary teams, including professionals from health, mental health, learning disability, education and social care services.<sup>12 13</sup>

### *Later life*

Sonido et al (2020)<sup>14</sup> summarise the available literature regarding older autistic adults over the age of 50, from 2010 to mid-2019. The authors suggest that, in general, there appears to be a positive impact, and relief, from receiving a diagnosis in adulthood 'with adults gaining a new understanding and re-interpretation of their life experiences'<sup>14</sup>

The report implies older autistic adults may experience greater or different challenges in several areas as they approach and experience later life, when compared to the general population e.g.,

- higher rates of some common health conditions,
- impact on cognitive functioning that is different,
- most studies consistently report higher lifetime rates of 'psychiatric comorbidity' and possibly higher rates of suicidal ideation.

However, more research is needed to improve our understanding of older autistic peoples' experiences of employment, social support and connectedness, use of transport and healthcare. The study also shows that carers of autistic people can feel anxieties about the future of the autistic person they care for, for instance, where they would live, what support would be available, and the impact on quality of life. These concerns vary depending on the different carer groups: sibling, parent or spouse.

### *The Growth Approach to Autism in Reading<sup>7</sup>*

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

As expressed in the Growth Approach to Autism in Reading, the shared view of autism is that:

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

The Growth Approach aims include:

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<sup>13</sup> NICE (2013). Overview | Autism spectrum disorder in under 19s: support and management | Guidance | NICE. [online] Nice.org.uk. Available at: <https://www.nice.org.uk/guidance/cg170>.

<sup>14</sup> Sonido, M., Arnold, S., Higgins, J. and Hwang, Y.I.J. (2020). Autism in Later Life: What Is Known and What Is Needed? Current Developmental Disorders Reports, 7(2), pp.69–77.

- The Reading community will grow a shared understanding of autism as a difference not a deficit.
- Staff across public services will be able to access high quality training and support to grow their skills and knowledge about autism and how to make their provision more accessible for autistic people and their families.
- Staff across public services will be able to access high quality training that grows their confidence and their ability to provide positive experiences for autistic people
- Children and young people will be supported to grow through consistent, research-based approaches in schools and settings that have been co-produced with autistic people themselves.
- The experiences children and young people have at school, in their homes and communities will grow; productive, confident, independent and authentic people who have been enabled to achieve equitable outcomes to their neuro-typical peers. They will have the tools and scaffolds they need and want to support them to self-advocate and self-regulate when they face any personal or institutional barriers or prejudice.
- Parents and carers will be supported to grow as experts in their child's needs. They will be able to access the information, support and advice needed, to help their child navigate through their childhood and dismantle any barriers they face.

Brighter Futures for Children will:

- ✓ facilitate the growth of education system leadership by building on existing expertise and providing networking opportunities
- ✓ facilitate the growth of networking opportunities for people within the autistic and neurodiverse community
- ✓ produce growth in the number of specialist education places
- ✓ provide support and training for new specialist resources to help them embed quality standards frameworks
- ✓ emphasise the importance of co-production, respect and communication

## 3 | Context

### 3.1 Purpose, goals and objectives

Needs assessment is a systematic method of identifying unmet needs of a population and making recommendations for changes to meet those needs. The purpose of this Needs Assessment is to identify recommendations, priorities and to inform Reading's forthcoming All-Age Autism Strategy which aims to improve outcomes for autistic people in Reading.

### 3.2 Aims and scope of this Needs Assessment

#### 3.2.1 Aims

The aim of this Needs Assessment is to provide a comprehensive assessment and understanding, where possible, of the needs of autistic people of all ages in Reading. In addition, to use available local and national data sources, to estimate the numbers of autistic people in Reading and how these numbers are predicted to change with time; identify the service assets and gaps currently provided, including the perspective and insights from autistic people and their Carers. The assessment will review evidence and aim to identify good practice in other areas Local Authority areas and use this resulting information to make recommendations and inform the developing local All Age Autism Strategy for Reading, supporting the improvement of outcomes for autistic people.

#### 3.2.2 Scope

This needs assessment will review the health, social, educational, employment, criminal justice and support needs including provision of services for autistic people in Reading, as well as accessibility of universal services for autistic people.

1. The needs assessment will consider the needs of autistic people in Reading of all ages, including those with or without a learning disability and/or other co-occurring conditions.
2. The needs assessment sets out to identify:
  - Estimated numbers of autistic people in Reading:
  - The needs of autistic people in Reading (with or without a formal diagnosis and including those who may not currently be accessing any services), and
  - likely future levels of demand for support and care.
3. The needs assessment will comprehensively map Reading services, needs and identify potential gaps and opportunities for improvement by engaging with autistic people, their families, carers and service providers.
4. The needs assessment will make recommendations for RBC, health providers and commissioners in terms of their statutory responsibilities and how to deliver these in partnership and to inform a strategy which aims to improve outcomes for autistic people in Reading.

The scope of this assessment covers the core areas outlined in the national strategy for autism discussed further below<sup>15</sup>

The recommendations from this needs assessment will be used to set objectives in Reading's Autism Strategy.

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<sup>15</sup> Department of Health and Social Care and Department for Education (2021). The national strategy for autistic children, young people and adults: 2021 to 2026. [online] GOV.UK. Available at: <https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026>.

### 3.3 National and local policy context

#### 3.3.1 Legislation, strategies, policies and guidance

Autism is a priority nationally as evidenced in various national legislation, strategies and policies.

##### *The Autism Act (2009)*

- places a duty on the Government to produce and regularly review an autism strategy to meet the needs of autistic adults in England.
- places a duty on the Government to produce statutory guidance for local authorities to implement the strategy locally
- places a duty on local authorities and NHS bodies to follow the national Strategy and make provision for meeting the needs of autistic adults.

##### *The National Strategy for autistic children, young people and adults, 2021-26*<sup>15</sup>

The current **National Strategy for autistic children, young people and adults, 2021** Error! Bookmark not defined. sets out the vision across six priority areas to transform the lives of all autistic people and their families over a 5-year period, from 2021-2026:

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

The strategy also highlights specific actions for national government and local authorities working in partnership with the NHS, the voluntary sector, as well as autistic people to achieve this vision. As required by the national strategy, Reading has a multi-agency Autism Partnership Board. A Reading's Autism Strategy for Children, Young People and Adults 2015 - 2018, was developed. The all-age strategy set out how we would comply with our statutory duties locally, and meet the commitments in other relevant national policies, such as the NHS Long Term Plan. The Autism Board is reviewing the current needs of autistic people in Reading and this all-age autism needs assessment is being conducted which will inform Reading's All Age Autism Strategy.

##### *National Institute for Clinical Excellence (NICE) guidelines*

NICE guidelines that address autism include:

###### *Children:*

- NICE. Autism spectrum disorder in under 19s: support and management (CG170) 2013.<sup>16</sup>
- NICE. Autism spectrum disorder in under 19s: recognition, referral and diagnosis (CG128) 20118

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<sup>16</sup> NICE (2013). Overview | Autism spectrum disorder in under 19s: support and management | Guidance | NICE. [online] Nice.org.uk. Available at: <https://www.nice.org.uk/guidance/cg170>.

### Adults:

- NICE. Autism spectrum disorder in adults: diagnosis and management (CG142) 2012<sup>17</sup>

These set out best practice expectations relating to:

- Reducing waiting lists
- Meeting the referral to diagnosis timescales
- CCG commissioning of assessment and diagnostic services

### Autism spectrum disorder overview (NICE) and specific guidelines include:

- [Service organisation and delivery for autism spectrum disorder](#)
- [Identifying possible autism spectrum disorder in under 19s](#)
- [Referral of under 19s with possible autism spectrum disorder](#)
- [Assessing autism spectrum disorder in under 19s](#)
- [Diagnosing autism spectrum disorder in under 19s](#)
- [Managing autism spectrum disorder in under 19s](#)
- [Behaviour that challenges in autistic people under 19](#)
- [Identifying, assessing and diagnosing autism spectrum disorder in adults](#)
- [Managing autism spectrum disorder in adults](#)
- [Behaviour that challenges in autistic adults](#)
- [Coexisting mental disorders in autistic adults](#)

Source: [Autism spectrum disorder overview - NICE Pathways](#)

**Statutory guidance for Local Authorities and NHS organisations (Department of Health, 2015)** sets out how the Adult Autism Strategy should be implemented.

**The NHS Long Term Plan 2019** commits to “do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, longer lives.”<sup>18</sup>

### Additional legislation and national guidance relevant to meeting the needs of autistic Children and Adults and their families

- ✓ The Chronically Sick and Disabled Persons Act 1970
- ✓ The Children’s Act 1989
- ✓ Health and Social Care Act 2012
- ✓ Children and Families Act 2014
- ✓ The Care Act 2014
- ✓ The SEND Code of Practice 2014
- ✓ Transforming Care
- ✓ Equality Act 2010
- ✓ Human Rights Act 1998
- ✓ Mental Health Act 1983
- ✓ The Mental Capacity Act 2005.

### 3.3.2 Local strategies

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

#### 1. Reduce the differences in health between different groups of people.

<sup>17</sup> NICE (2012). Overview | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE. [online] Nice.org.uk. Available at: <https://www.nice.org.uk/Guidance/CG142>.

<sup>18</sup> NHS (2019a). NHS Long Term Plan. [online] Available at: <https://www.longtermplan.nhs.uk/online-version/>.

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

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

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

- Healthy environment
- Thriving communities
- Inclusive economy

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

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

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

The strategy aims to make SEND, including autism, everybody's business by embedding it in the practice of all those that work with children, young people and families. The aspiration is to improve outcomes for children and young people by focusing on working together to deliver the right support in the right place at the right time, foster independence, and ensure their emotional, social and physical health needs are met. Additionally, to have access to universal and specialist services "to lead rich and fulfilling lives and flourish in a healthy, thriving and inclusive borough".<sup>20</sup>

### 3.3.3 Guidance and best practice for supporting autistic people

Below is a summary of the actions recommended in various guidance and best practice resources in relation to autism and support offered.

#### *Existence of an **Autism strategy group (all ages)***

- Responsible for developing and monitoring effectiveness of care pathways.
- Appoint a lead professional to be responsible for the local autism pathway for recognition, referral and diagnosis of children and young people.
- Representation should be multi-disciplinary, including managers, commissioners, clinicians, social care, housing, criminal justice system, education, employment and the voluntary sector.
- Meaningful representation from autistic people, their families, partners and carers.
- Raising awareness – multi-agency training, making sure relevant professionals are aware of the pathway

<sup>19</sup> BFfC are a company limited by guarantee, wholly owned by Reading Borough Council, but run by an independent Board of Directors.

<sup>20</sup> 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/> [Accessed 3 Mar. 2022].



- 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)<sup>8</sup>
- Training, including professionals knowing how to access services

### ***Autism team (CG128 – identifying and diagnosing young people)<sup>8</sup>***

- Provide a single point of contact for referral
- Multidisciplinary team comprising paediatrician or child and adolescent psychiatrist, speech and language therapist and clinical or educational psychologist.
- Either include or have access to a paediatrician or paediatric neurologist, child and adolescent psychiatrist, educational psychologist. Consider including other relevant professionals such as specialist health visitor, nurse, teacher or social worker.
- Skills and competencies to carry out an autism diagnostic assessment and communicate with autistic children and young people and sensitively share diagnosis, including where there are co-existing conditions
- Provide advice to professionals about whether to refer children and young people for autism diagnostic assessments
- Decide on assessment needs/referral to another service
- Carry out the autism assessment and share the outcome as appropriate with parents, Carers and other services (such as school).
- *Post diagnosis* - Offer information and advice about appropriate services and support.

### ***Diagnosis***

- Professionals are advised to consider assessment if they recognise key traits of autism. Criteria for assessment are different for adults and children and young people. For adults without LD or with mild LD, the AQ-10 assessment tool is used.
- For those with moderate or severe LD, using information from family, partner or Carer.
- Professionals working with children and young people are advised to take parents' and carers' concerns seriously and discuss with both them and the young person.

### ***Interventions***

- ***Psychosocial interventions***

- **CYP**

- Play-based strategies to increase joint attention, engagement and communication (YP CG170)<sup>16</sup>

- **Adults**

- Group based social learning programme focused on improving social interaction, or individual delivered for people who find groups difficult. Includes modelling, [peer] feedback, discussion and decision-making, rules, strategies for dealing with socially difficult situations.
  - psychosocial interventions focused on life skills/activities of daily living e.g. leisure activity programme (no LD or mild/moderate)
  - anger management intervention (no LD or mild/moderate) includes coping skills, problem solving and relaxation training
  - anti-victimisation and personal safety skills
  - employment programme

- ***Pharmacological, physical and dietary***

- None recommended.

- ***Anticipating and preventing behaviour that challenges***

- **CYP**

- Assess factors that may increase risk in routine assessment and care planning, including communication resulting in difficulties in understanding, coexisting physical disorders,

coexisting MH disorders, physical environment (lighting, noise), social environment, changes to routine, development change, exploitation or abuse, inadvertent reinforcement, absence of structure **(CG170)**<sup>16</sup>

- Psychosocial interventions as first line treatment
- Pharmacological interventions – antipsychotic medication

#### **Adults**

- Address triggering factors
- Physical disorders
- MH disorders, treatment psychological and pharmacological
- Interventions to change physical or social environment
- Psychosocial interventions – identify target behaviour, QOL outcomes, modification of environment, intervention strategy, schedule of reinforcement, timescale and measures
- Antipsychotic medication and psychosocial intervention when no response to psychosocial or other
- Antipsychotic medication alone when others could not be delivered because of severity
- Adapted psychosocial interventions for co-existing MH disorders

### **Families and Carers**

#### **CYP**

- Provision of an assessment of own needs offered to families (also siblings) and carers, including whether they have:
- Personal, social and emotional support
- Practical support in their carer role
- A plan for future care – including transition to adult services for CYP **(CG170)**<sup>16</sup>

#### **Adults**

- Provision of verbal/written information about autism and its management
- For Right to a carer's assessment of their own needs (physical and mental health) and how to access this.
- Support groups for families and carers<sup>17</sup>

### **Transition to adult services**

- 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

### **Other steps to implement to support transitions**

- Provision of support at university and help available through Disabled Students Allowance.
- Reasonable adjustment in Year 6 SATs (not public exams e.g., extra time, use of a laptop, separate invigilation).

## 4 | Health

### 4.1 Diagnosis - Children and young people

#### 4.1.1 Referral and Assessment

The autism diagnostic pathway for children and young people in Reading is designed to be **needs led** rather than **diagnosis dependent** support (for example, through the [Graduated Response](#) for Early Years and Schools) and much of the same support available after an autism or ADHD assessment is also available before and during the assessment. Autism assessment is via a specialist team. Demand for assessment for Children and Young People (CYP) exceeds capacity of the service, in common with many other parts of the country.

NHS Berkshire West CCG covers the Reading, Wokingham and West Berkshire local areas and commissioning of services is normally on a Berkshire West footprint. The provider of Children and Adolescent Mental Health Services (CAMHS) and the Children Young People and Families (CYPF) service (which included the Neurodiversity Service) is Berkshire Healthcare Foundation Trust under a block contract arrangement.

Berkshire Healthcare NHS Foundation Trust provides the assessment pathway for any child aged 0-18 years. Young people aged 17 ½ years and older are referred directly to the Adult Autism Assessment team. Once a referral is accepted by the CYPF Neurodiversity Service they will complete the assessment even if the young person has turned 18 years while waiting. The team includes Community Paediatricians, Clinical Psychologists, specialist Speech and Language Therapists and other specialist practitioners. Depending on a child or young person's need, they may be referred for further support from CAMHS and/or the Children and Young People's Integrated Therapies (CYPIT) team – including Speech & Language Therapy, Occupational Therapy, Physiotherapy, and Specialist Dietetics services. To access the Autism Assessment Team, referrals are accepted from professionals who know the child or young person, including health visitors, nursery nurses, teachers, school nurses, special educational needs coordinators (SENCO), educational psychologists and GPs. Ideally referrals should come from professionals that know the child best, such as their teacher, SENCO, speech and language therapist or health visitor.

[Referrals to the children, young people and families service in Berkshire can be made here \(berkshirehealthcare.nhs.uk\)](http://berkshirehealthcare.nhs.uk)

In many areas Autism Assessment and ADHD teams sit within CAMHs. BHFT have a separate neurodiversity service which sits alongside and works very closely with CAMHs but is a separate service. This is to reflect that while some autistic people or ADHD may have a co-occurring mental illness; autism and ADHD are neurodivergent conditions. The model adopted for diagnosis and ongoing support is shown below.

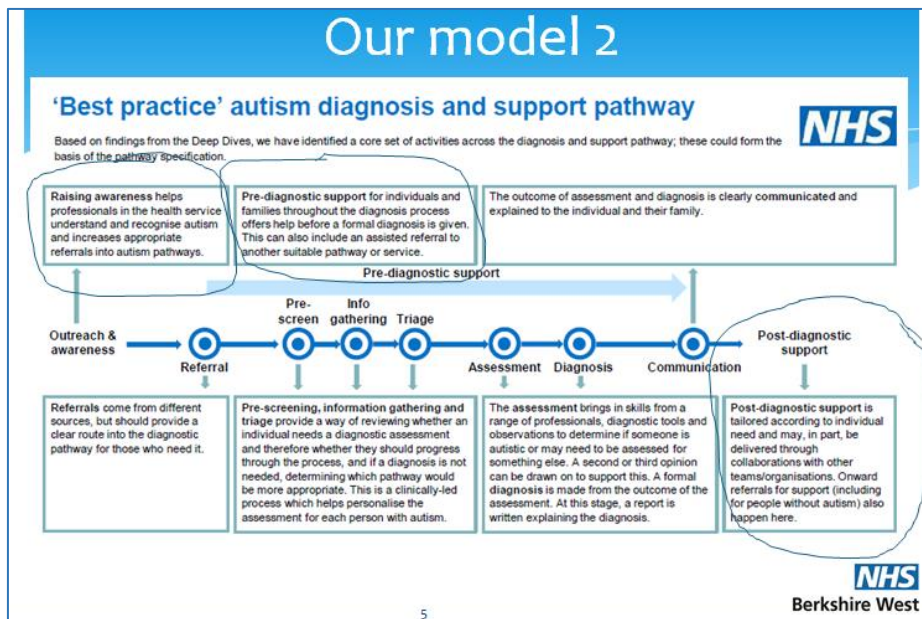


Figure 1. 'Best practice' autism diagnosis and support pathway for CYP, NHS Berkshire West

### Referrals and waiting times - 2016/17 to 2021/22 - Berkshire wide and Reading only

In the last 5 year period, across Berkshire for CYP, there has been an increasing trend of ADHD 6-18 year caseload (open for treatment) from 1736 people in 2016/17 to 3749 in 2021/22. Autism assessment referrals, Berkshire wide, increased from 1209 in 2016/17 to 2045 in 2021/22.

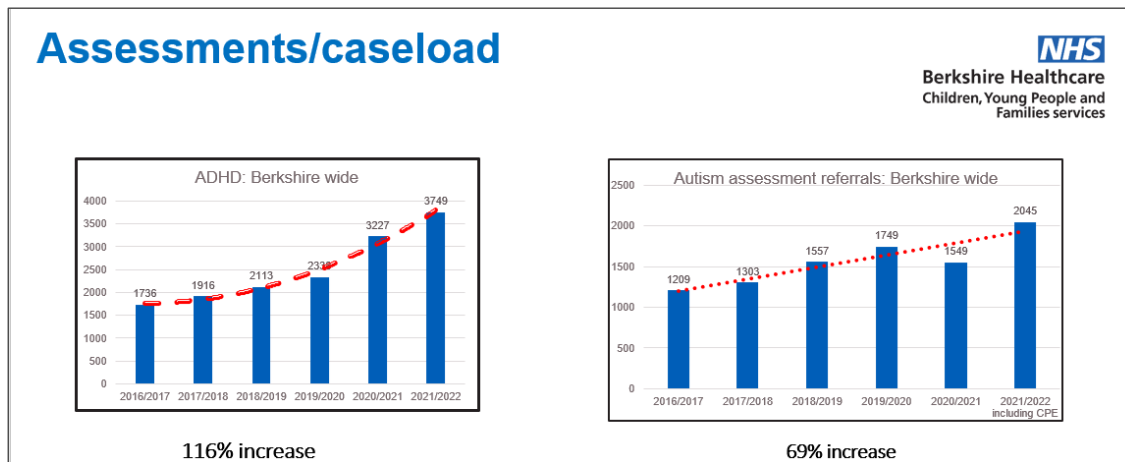


Figure 2. Referral trends for Autism and ADHD, 2016/17 – 2021/22, Berkshire Healthcare CYPF service

ADHD 6-18 year caseload trends (open for treatment) indicate a 116% increase from 2016/17 to 2021/22. The second chart for Autism assessment referrals, Berkshire wide indicate a 69% increase in autism assessment referrals from 2016/17 to 2021/22. (Incl. CPE).

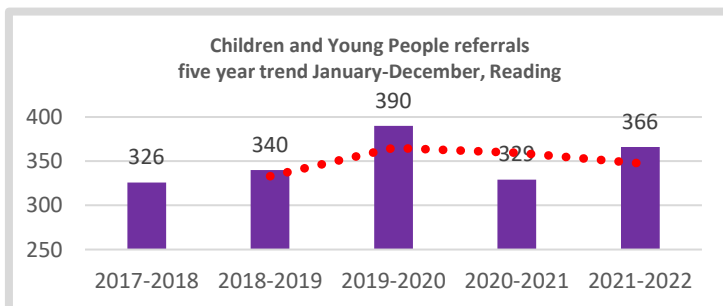


Figure 3. Children and young people referral, 5 year trend for Autism, 2017/18 – 2021/22, Reading

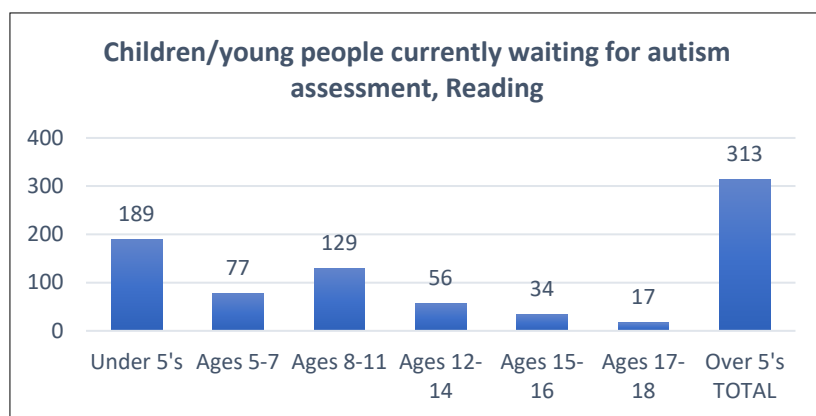


Figure 4. Children and young people currently waiting for autism assessment, Reading, (as at March 2022)

#### 4.1.2 Ongoing Support for Children and Young People

Berkshire West CCG commission an autism/ADHD pre assessment and post diagnostic support service for children and young people up to the age of 25 years and their families. This forms part of Reading's needs led response regardless of diagnosis. Autism Berkshire work in partnership with Parenting Special Children to provide the Autism and ADHD support service for families of children and young people at any point in their journey.

In Reading, varied support is available for both autistic children and young people at pre-diagnostic and post-diagnostic stages and is tailored to needs. Information about the assets and resources currently available is provided below. Local insight indicates that the assessment process can be complex and very long, with many reporting waiting periods between referral, first appointment and other appointments and they may not be aware of the support that can be accessed during this time. There is scope for clearer sign posting to existing groups and services including peer support, as well as the provision of updates to those on waiting lists (for example via websites) to ensure they do not "feel forgotten".

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

All details of the training offered can be found at:

<https://brighterfuturesforchildren.org/professionals/school-standards-services/school-standards-service-a-growth-approach-to-autism/>

*Berkshire Healthcare Foundation Trust for Children and Young People*

- **SHaRON online support network:** (Support, Hope and Resources Online) is a secure online support platform for parents and carers of young people with an ADHD and/or autism diagnosis or who are waiting for either/both assessments. SHaRON is available from the point of referral onwards and is moderated on a regular basis by the ADHD & Autism Assessment Team clinicians, voluntary agencies such as Autism Berkshire and Parenting Special Children and other professionals from across Berkshire. Most importantly other parents and carers are also there to share their own experience, advice and questions. This connects individual to each other as well as to the service, offering peer to peer support as well as prompt access to professionals and a comprehensive library of self-help resources. Available 24/7 365 days a year.
- **Qualified and trainee Children's Wellbeing Practitioners** provide brief evidence-based interventions (for anxiety, low mood and emotional dysregulation) for children, young people and their parents (available pre assessment)

- **A Helpline is provided by the CYP service** to respond to new or increasing concerns for families and/or professionals; this provides support, advice, signposting, onward referral as needed along with decisions about prioritisation of the assessment
- **Referral packs give information** on all sources of family support to ensure families access this as soon as possible. Also contains a **letter for school to emphasise need for needs-led support**
- **Comprehensive online resource** with help and advice on a wide range of developmental, emotional/mental health etc concerns  
[Support and advice | Children Young People and Families Online Resource \(berkshirehealthcare.nhs.uk\)](http://berkshirehealthcare.nhs.uk)  
[Mental and Emotional Health | Children Young People and Families Online Resource \(berkshirehealthcare.nhs.uk\)](http://berkshirehealthcare.nhs.uk)  
[Health and Development | Children Young People and Families Online Resource \(berkshirehealthcare.nhs.uk\)](http://berkshirehealthcare.nhs.uk)
- Support is provided according to needs by a range of services including Children and Young People's Integrated Therapies (CYPIT), CAMHS (including Mental Health Support and Getting Help Teams), Health Visiting and School Nursing depending on needs.
- **Psychological Perspectives in Education and Primary care (PPEPcare)** – for schools, GPs and other agencies - equips settings to provide needs led support (autism awareness, autism and mental health and ADHD modules).  
[Services for professionals: PPEPCare Training | Children Young People and Families Online Resource \(berkshirehealthcare.nhs.uk\)](http://berkshirehealthcare.nhs.uk)

*Berkshire West Autism and ADHD Support service*

[Click here](#) to download a leaflet about the service and the support available.

The service is accessed by self-referral or referral by professionals and provides

- Advice and support
- Workshops/courses/activities for families and for children and young people aged 5 to 25 who are autistic and/or have ADHD or who are waiting for assessment

**For parents and carers, support available includes:**

- [Home Visits](#) – an in-depth one-to-one discussion online or face-to-face (where possible) with parents and carers
- [ADHD advice workshops](#): An Introduction to ADHD; Anxiety and ADHD; Managing ADHD Behaviours
- [Autism advice workshops](#): Understanding More About Autism; Sensory Differences; and Supporting Behaviour
- [Teen Life](#), a NAS course for parents and carers of autistic children aged 10 to 16
- [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
- [SocialEyes](#), a NAS course for autistic 17 to 25-year-olds, looking at further social interaction skills and strategies to boost wellbeing and independence

## Reading Brighter Futures for Children

Within Reading's Brighter Futures for Children there is one Autism Advisor. The advisor supports all families in Reading that receive a diagnosis of Autism for their child through offering:

- Home Visits
- Living with Autism course
- Family Seminars
- Coffee Mornings
- Advice to families & professionals

The CYP Autism Assessment Team signpost to this service when making a diagnosis and, if appropriate consent is obtained, will also share a copy of the assessment report (or a brief letter confirming that a diagnosis has been made). The Advisor sends all families a letter offering an at home meeting or virtually. All families are offered the option to attend a six week Living with Autism course and the Advisor remains a point of contact for all parents/carers in Reading that have an autistic child. This will include anyone new to the area or anyone that has received a private diagnosis, which has been becoming more common due to the wait times.

This is a valued service as the Advisor can support the communication between family and other professionals and ensure families are linked with the right services. Since the COVID-19 pandemic and the delay between appointments, the Advisor has been offering support to families that have yet to have the second part of their assessment.

## 4.2 Diagnosis - Adults

### 4.2.1 Referral and Assessment

For adults, Berkshire Healthcare NHS Foundation Trust provide an Autism Assessment Service. Referrals are accepted for those aged 17 ½ years old and above from GPs through the Common Point of Entry (CPE) service and other teams within Berkshire healthcare. All clients are sent screening questionnaires to help decide if a referral to the Adult Autism Assessment Team is indicated. Self-referrals are not accepted. The Adult Autism Assessment Team referral form can be found [here](#). The team includes Clinical Psychologists and specialist Speech and Language Therapists.

#### Adult Pathway to services

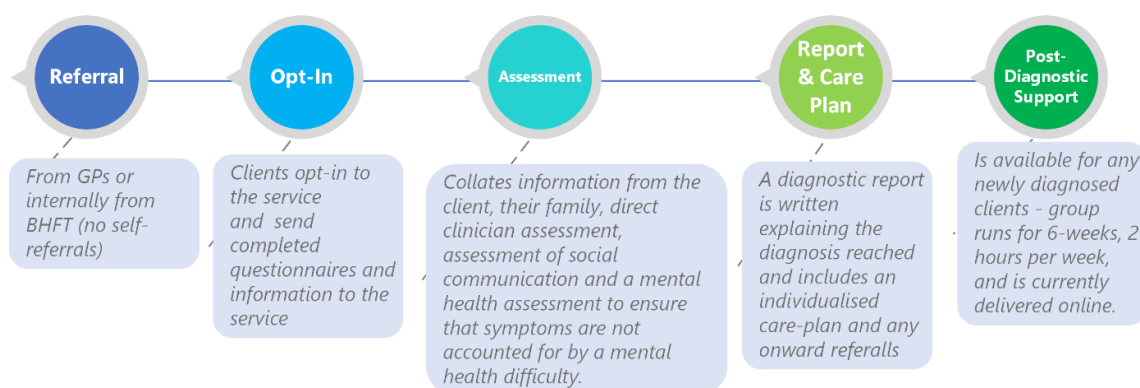
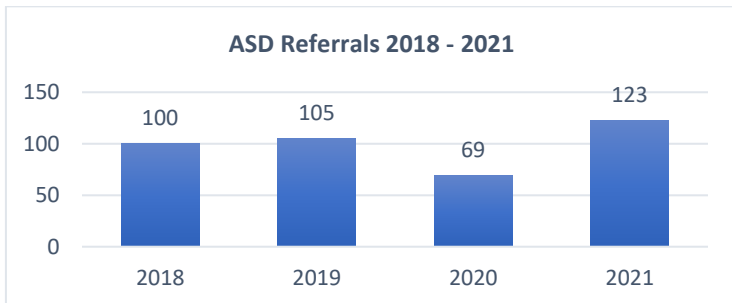


Figure 5. Adult pathway to services

*Referrals and waiting times*

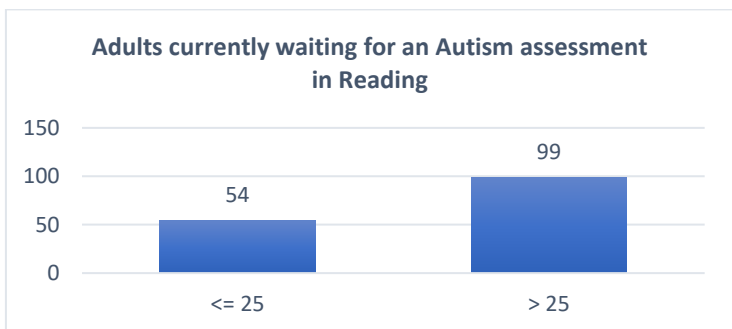
The number of referrals into adult autism services is much lower than the number for children. Although waiting times for some adults were shorter than those reported for children – around a third waiting six months or less – around a third of those seen by the service since 2018 have waited two years or longer.



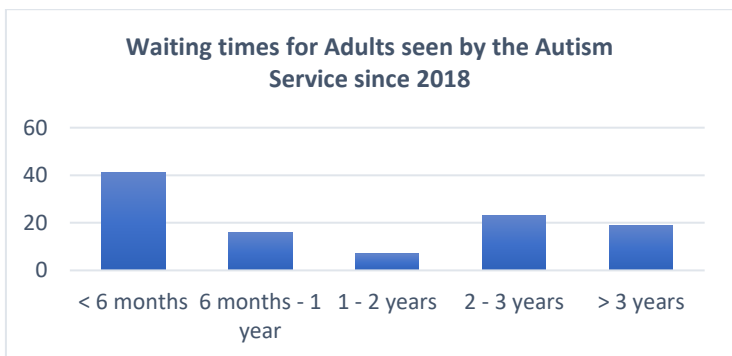
*Figure 6. Adult referrals for Autism, 2018 – 2021, Reading*



*Figure 7. Adult ASD referrals grouped by age, 2018 – 2021, Reading*



*Figure 8. Number of adults on the waitlist for ASD assessment, Reading, aged under and over 25 years.*



*Figure 9. Time from referral to appointment for clients seen by the Adult ASD service 2018 – 2022*



## 4.2.2 Ongoing support for adults

### *Berkshire Healthcare Foundation Trust*

For adults, Berkshire Healthcare NHS Foundation Trust run an Autism Service and also offers post diagnostic group support. Adults diagnosed with autism by the BHFT Adult Autism Service, can access a 6 week post diagnostic support group.

Following an assessment, clients receive a tailored care plan which may include:

- A referral to Talking Therapies for a range of therapies, including cognitive behaviour therapy and counselling, may be made if appropriate. The adult autism team offer one consultation to a therapist working with autistic clients that have been diagnosed by our service.
- Referral for a social care needs assessment
- Reading recommendations for various aspects of autism e.g., masking, sensory sensitivities
- A letter to share with an employer or educational provider regarding the diagnosis and reasonable adjustments
- Advise for the GP in understanding autism.

### *Adult Social Care*

A diagnosis of autism may trigger an offer of a care assessment by Reading Borough Council Adult Social Care. Following a diagnosis of autism, adults can also access post diagnostic specific or reasonably adjusted psychology assessments, speech and language therapy assessments, and occupational therapy assessments, whether or not they also have a learning disability diagnosis. The number of people with an autism diagnosis who met Care Act eligibility criteria for Adult Social Care support in the last year is however unknown.

## 4.3 Waiting times data for adults and children

The data that follows presents a group of measures on waiting times for autism assessment pathways, based on the time between a referral for suspected autism and the first care contact associated with that referral. Each of these measures contributes to an overall picture of waiting times for diagnostic pathways.

### *Limitations of data and interpretation issues:*

*“These are Experimental Statistics and are being published to involve users and stakeholders in their development and to build in quality at an early stage. As such, they remain under constant review.*

*There are known data quality limitations with respect to the completeness of care contacts and specific information related to these, such as the specific team that referred the patient or the presence of a formal diagnosis. For these reasons, these statistics do not yet represent a complete picture of autism diagnostic pathways. There are records with a missing care contact date and so waiting times between referral and first care contact cannot be derived for some patients within the forward model.”<sup>21</sup>*

**Figure 12** indicates that in quarter 1, 2021/22 there were **775** people in Reading, who have been referred for an autism assessment and are awaiting a diagnosis.<sup>21</sup> Overall, as shown in **Figure 10** and **Figure 11**, it can be seen that at a Berkshire West CCG level, referrals for autism assessments have been increasing from 2019/20 – 2021/22 and with each quarter and similarly at a provider level (Berkshire Healthcare NHS Foundation Trust).

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<sup>21</sup> NHS Digital (2022). Autism Statistics Quarter 1 (April to June) 2019-20 to Quarter 1 (April to June) 2021-22. [online] NHS Digital. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/autism-statistics/quarter-1-2019-20-to-quarter-1-2021-22#> [Accessed 22 Jan. 2022].

**New referrals, by Clinical Commissioning Group (CCG)<sup>21</sup>**

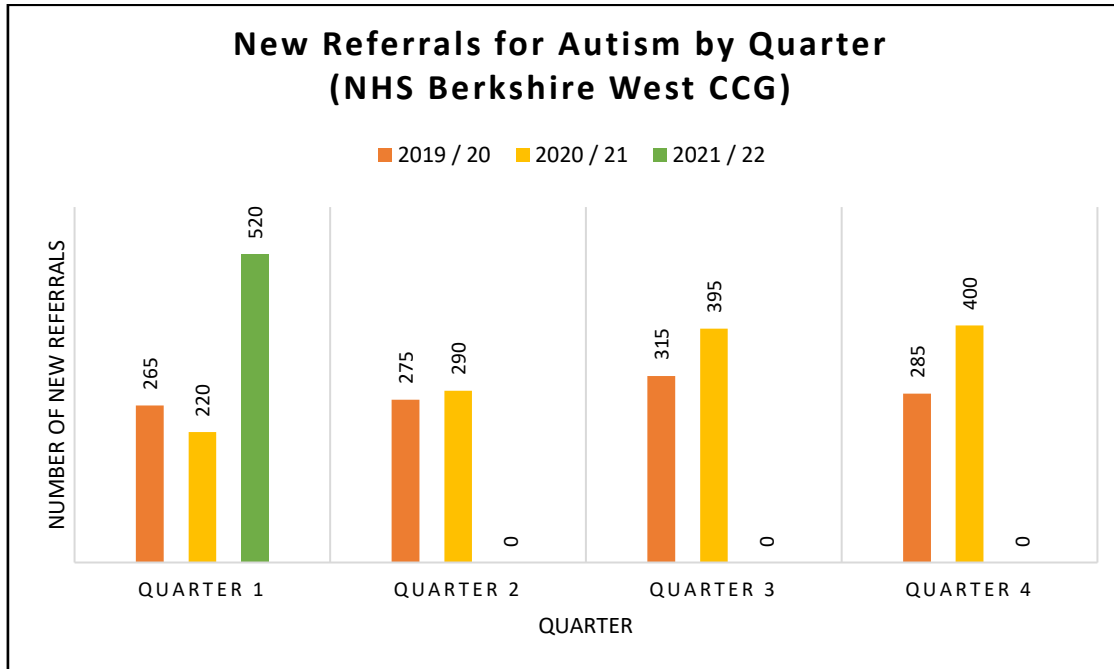


Figure 10. New referrals for autism by quarter, 2019/20 - 2021/22, NHS Berkshire West CCG (Source: NHS Digital)

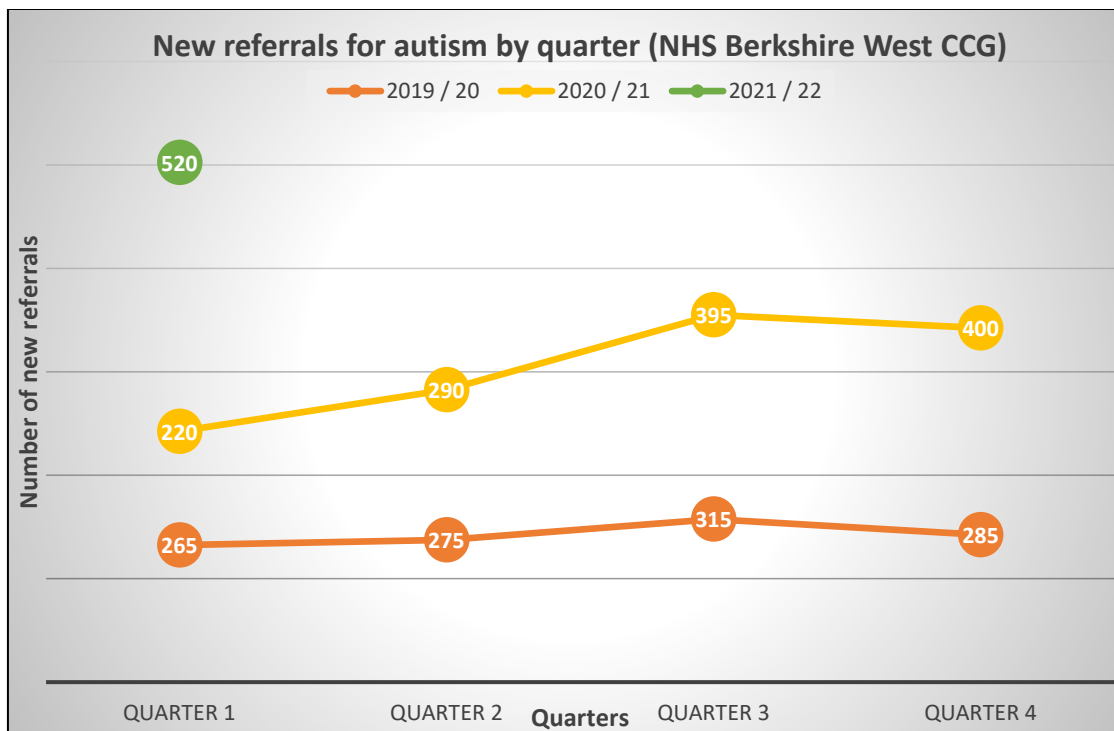


Figure 11. New referrals for autism by quarter, 2019/20 - 2021/22, Trend, NHS Berkshire West CCG (Source: NHS Digital)

**New referrals, by Reading Provider**

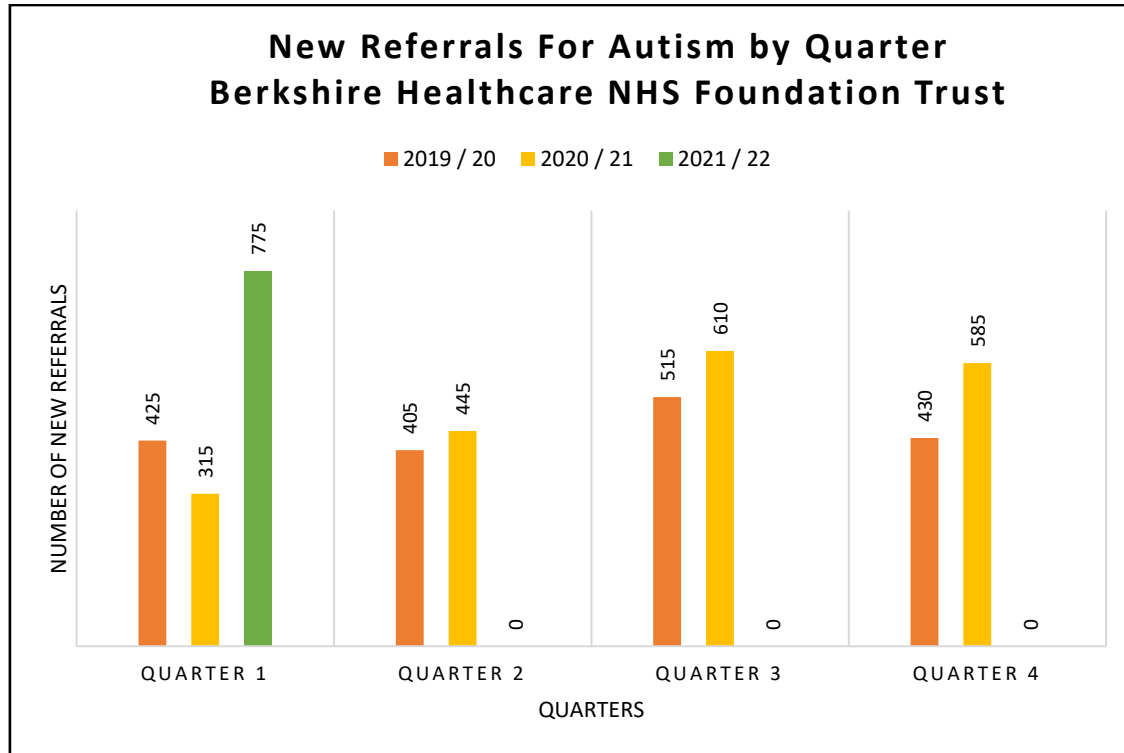


Figure 12. New referrals for autism by quarter, 2019/20 – 2021/22, Berkshire Healthcare NHS Foundation Trust

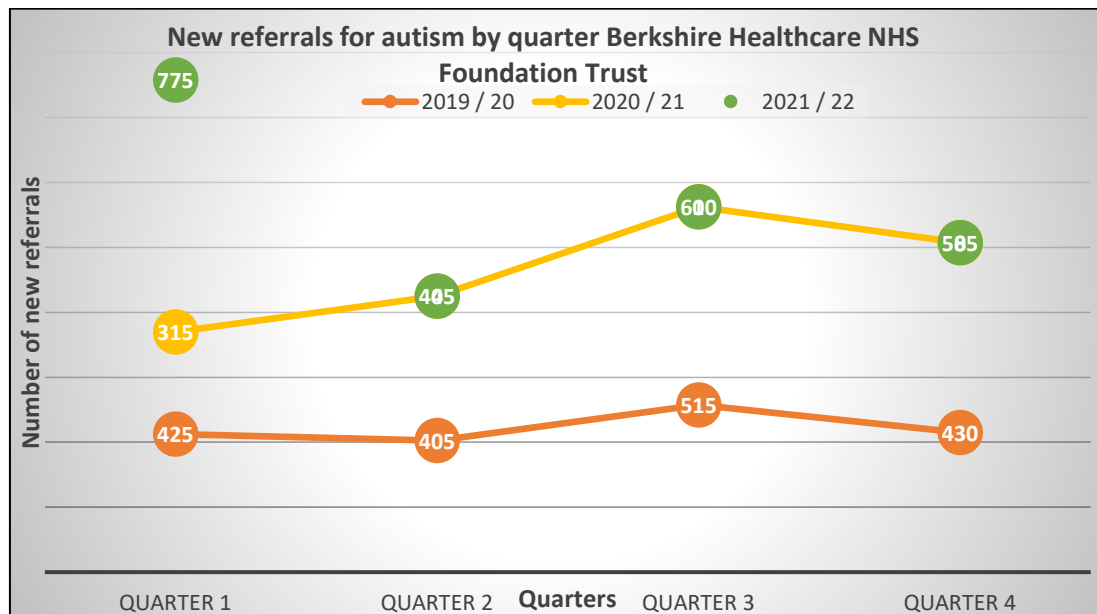


Figure 13. New referrals for autism by quarter, 2019/20 – 2021/22, Trend, Berkshire Healthcare NHS Foundation Trust

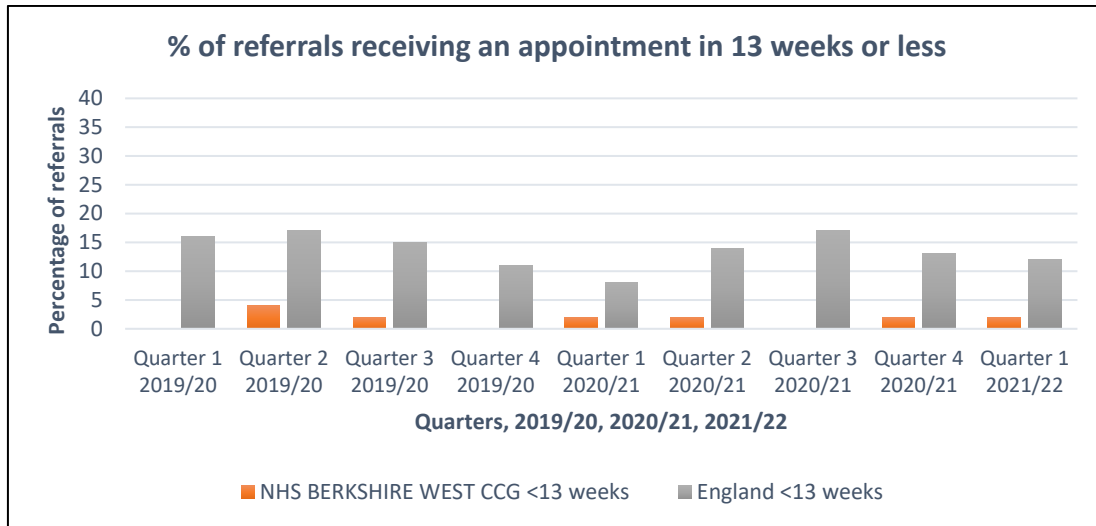


Figure 14. Percentage referrals for autism receiving appointment in  $\leq 13$  weeks, 2019/20 – 2021/22, NHS Berkshire West CCG

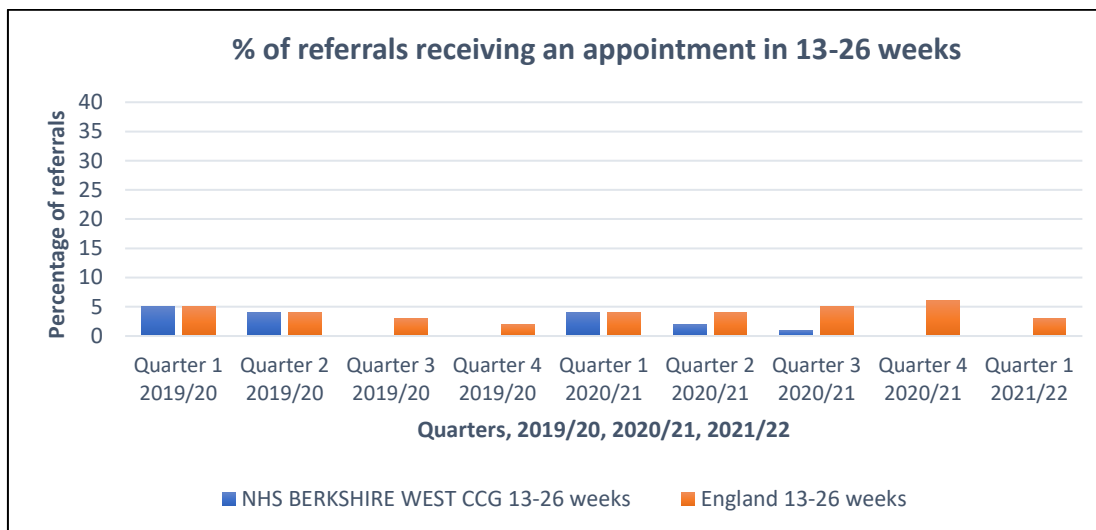


Figure 15. Percentage referrals for autism receiving appointment in 13-26 weeks, 2019/20 - 2021/22, NHS Berkshire West CCG

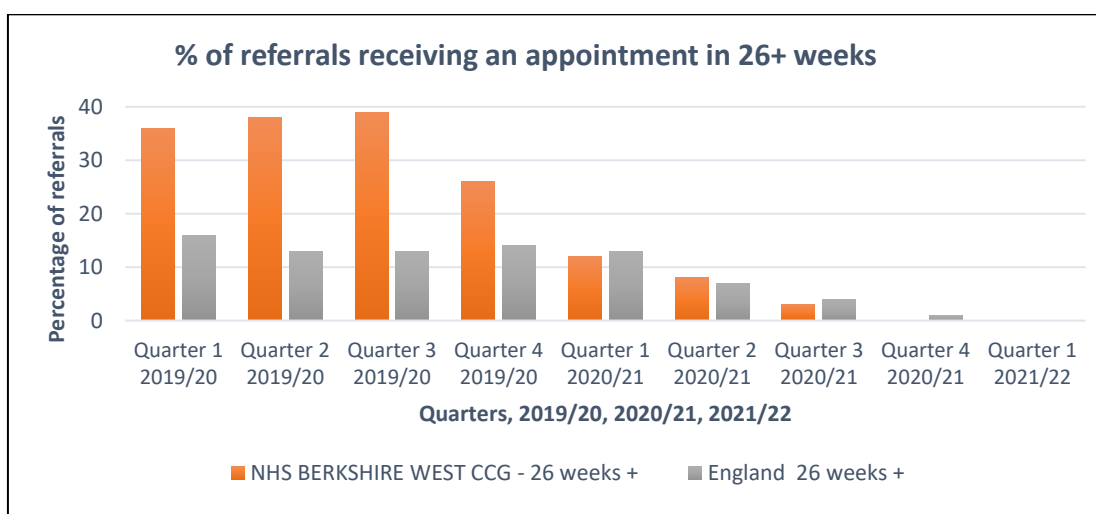


Figure 16. Percentage referrals for autism receiving appointment in 26+ weeks, 2019/20 – 2021/22, NHS Berkshire West CCG

As can be seen in **Figure 14**, **Figure 15** and **Figure 16**, there continue to be large numbers waiting and long waits due to the high demand on the service, which significantly outstrips the service capacity. This is due to several factors including high demand for the service, increased

clinical complexity, the impact of the pandemic and national recruitment challenges. The Care Quality Commission (CQC) are aware of this issue.

In partnership with East Berkshire CCG and Berkshire West CCG, BHFT have completed comprehensive demand, capacity, workforce and transformation modelling and have subsequently received significant new investment for the service. A costed proposal to reduce waiting times to a sustainable 12 months has been taken through CCG and BHFT governance and an additional investment of £800K in 21/22 was provided to reduce waiting times and this will increase to £1.6M FYE for the following year. The new investment is enabling a significant service expansion across the Autism Assessment Team (AAT) and the ADHD Team. The service is using the new investment both to increase the workforce and to use partnership working with external providers to increase the service capacity. This will significantly increase the number of appointments the service will be able to offer. The team also operate with a culture of continuous improvement to ensure optimal service delivery i.e., minimising waste and maximising efficiency and achieving a reduction in waits/variation in waits (using lean methodology).

Additionally, the Berkshire West, Oxfordshire and Buckinghamshire (BOB) Integrated Care System submitted an implementation plan for Autism and Learning Disability to NHSE/I where reducing waits for assessment is an action in line with the NHS Long Term Plan, along with a range of other initiatives for this population.

#### *Impact of Covid-19 (BHFT)*

While presenting unprecedented challenges for NHS services, the pandemic has also resulted in opportunities to innovate and learn valuable lessons to improve service delivery and offer more flexible access. Service development accelerated in terms of digital solutions (both provided by Berkshire Healthcare and external providers) The service adapted well and staff quickly embraced new ways of working and became skilled in online delivery and making greater use of technology.

- Online then blended offer (digital and face to face) - the service operated throughout
- Common Point of Entry –unprecedented increase in demand
- Less system support for families at a time of increased concerns
- Helpline (Care of People Waiting) increased (to daily support at times)
- Clinical contacts increased in duration/frequency with extra time needed to support families
- Clinical time needed to be used in the development of new ways of working and retraining (particularly relating to the direct assessment of children/young people in a Covid-19 safe and clinically robust way)

#### *Local data on waiting times*

**Figure 17** and **Figure 18** indicate that most new referrals into BHFT for suspected autism in 2019/20, received a first appointment after more than 26 weeks with a small proportion of referrals receiving their first appointment within 13 weeks or less and between 13 weeks and 26 weeks. In 2020/21 however, an improvement is seen with more referrals being seen within 13 weeks or less and between 13 weeks and 26 weeks, in comparison to 2019/20. However, overall, most referrals are still seen after more than 26 weeks from referral for suspected autism and the first care contact.

## Referrals for suspected autism receiving a first appointment, by waiting time

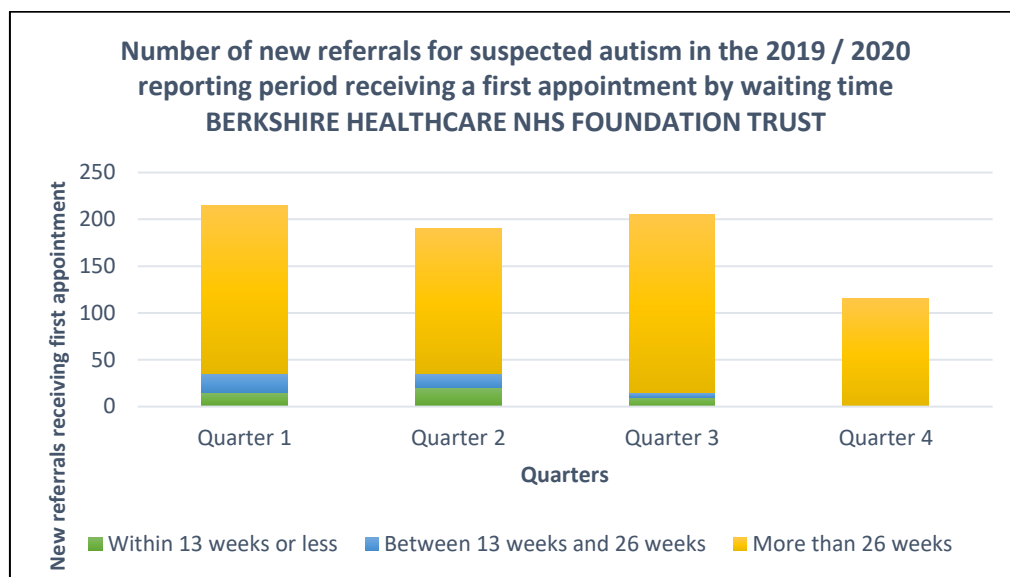


Figure 17. Number of new referrals for suspected autism receiving a first appointment, by waiting time, 2019/20, Berkshire Healthcare NHS Foundation Trust (Source: NHS Digital)

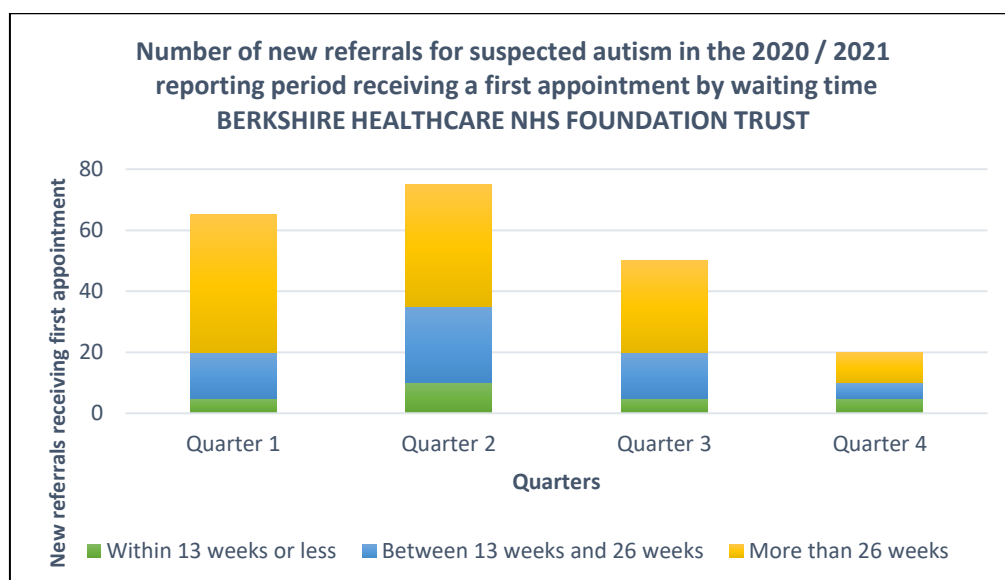


Figure 18. Number of new referrals for suspected autism receiving a first appointment, by waiting time, 2020/21, Berkshire Healthcare NHS Foundation Trust (Source: NHS Digital)

Through the early stages of the coronavirus pandemic, referrals for suspected autism dropped. We can see that while the number of providers submitting did not decrease significantly in quarter 1 2020/21, the volume of referrals for suspected autism submitted did. Referrals in 2021/22 are however showing an increase and it is likely that the closure or reduced operating of school throughout the 202/21 affected the referral pattern and this has now increased again.

Every child or young person should have a case manager or key worker responsible for coordinating their care. In addition, local autism teams should have oversight of the interventions and care of autistic children in their locality with particular needs, including children and young people who are looked after by the local authority, children who have immigrated to the UK, and children with severe co-existing conditions.<sup>16</sup> The difficulty we have locally is that BHFT do not commission this service and referrals may be incorrectly made to Children’s Social Care.

Continued multi-disciplinary autism assessments are imperative and children may be required to attend various separate appointments with different professionals, with very long waiting times for initial assessment, even up to two years. Post-diagnostic support is vital.

#### 4.4 Recommendations

- **Continue with the work on changing the culture across the system**  
Working across system to achieve a culture shift moving towards **needs led** rather than **diagnosis dependent** support and with a recognition of neurodiversity (difference rather than deficit)
  - Accessing help based on need, as early as possible
  - Promoting acceptance of neurodiversity
  - Strength based approach
  - Shared language
- Additional rollout and promotion of training for front-line staff and schools and early years' settings to improve early recognition of autism through raising awareness of signs and symptoms.
- Due to the pressing need to reduce waiting times, and link people into appropriate support more quickly following assessment and diagnosis, additional action is needed to facilitate this such as through the recruitment of additional Autism Advisors
- Where appropriate, clearly sign post autistic people and their families to sources of information and support.
- Develop a communication protocol between professionals and suspected autistic people and their families throughout the pre and post diagnostic journey (careful balanced between supporting families waiting and reducing the waits as additional time spent here may reduce assessment capacity).
- Ensure resources within Community Paediatrics can meet the demand for assessment.
- The level of support available for autistic people and their families should be proportionate to the demand for services.
- Consider dedicated autism support within educational settings pre and post diagnosis to facilitate in narrowing the gap and increasing support networks.

#### 4.5 Specialist Care, Health and support

##### 4.2.1 Children and young people

###### *Family and carer support*

Brighter Futures for Children (BFfC) has a Children and Young People's Disability Team which provides assessment and care management to disabled children and young people with complex needs, up to the age of 25 who are eligible for social care support. BFfC provides support for autistic children and their families post-diagnosis, including a home visit, a free Introduction to Autism Course, and an ongoing point of contact. The team can help families to access support in the community such as Short Breaks provision.

For families who need additional help, Children's Action Teams provide guidance and support. 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 courses run by local voluntary sector organisations. The CCG commissions **Autism Berkshire** to work in partnership with **Parenting Special Children** to provide a wide range of services for CYP aged 0-25 and their families.

## *Educational settings*

Most autistic children in Reading are in mainstream education. Schools can access support from Educational Psychologists, Speech and Language and Occupational Therapy for pupils who need this. Mental Health support in schools for autistic children and young people has increased, but there is still high demand.

Reading has a range of specialist education provision across all school years, including the Thames Valley School which currently supports children with an Education, Health and Care Plan (EHCP) 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 autistic pupils alongside mainstream education provision.

Autistic children with a learning disability or additional complex needs can 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.

Autism Berkshire, commissioned by BHFT, provides a range of provision for CYP and their families including **National Autistic Society (NAS) Teen Life, NAS sensory needs, NAS managing anger, NAS Understanding Autism, Social Interaction Groups, Social Eyes, Autism and Girls, Food Refusal, Emotional Regulation, Sleep Difficulties, Transitions** as well as individual sessions and support.

Reading operates a diagnosis process in accordance with NICE guidance for CYP.

## *Alternatives to Admission*

In 2019, Berkshire Learning Disability and Autism Board (formerly Berkshire Transforming Care Board) took the decision to focus efforts on strengthening community service provision which would enable both autistic adults and children or those who have a learning disability and behaviours that challenge, to live full and safe lives in their own homes, help to prevent unnecessary hospital admission, and to make it easier for people to be discharged from hospital as soon as they were ready. The Alternatives to Admission project was commissioned to work with stakeholders to identify the gaps in community service provision, explore examples of good practice and shape the case for developments in Berkshire.

### *What was done?*

The project was established to:

*Work with stakeholders across Berkshire, to develop a business case proposing the community developments needed to prevent unnecessary admissions to hospital for autistic or people who have a learning disability and behaviours that challenge. For children, prevention of admission to residential placements is also included. The case for development aimed to set out expected investment and impact in terms of improved outcomes and longer-term cost savings. Options for resourcing developments were considered, accepting that some funding opportunities may emerge at a later date and the existence of a clear strategic case aiming to support future bids.*

The project worked with stakeholders across health, social care, education and with families in East and West Berkshire to gather views and experience about the needs of autistic children and adults or those who have a learning disability and behaviours that challenge, how services meet those needs, and where there are gaps. The focus has been on those children or adults whose needs are most challenging and where new approaches could reduce the risk of escalation, avert a crisis, and avoid unnecessary admission to hospital, or residential settings in the case of children. The project researched examples of approaches in other areas, sharing information with local stakeholders to inform discussion and shape proposals.

Information gathering and discussion took place through:



- One to one or small group interviews and workshops with practitioners and families
- Regular engagement at SEND Boards, Local Transformation Groups (children's mental health), Learning Disability and Autism Partnership Board and Joint Operational Group
- Wokingham Learning Disability Partnership Board
- Task and Finish Groups in East and West Berkshire to jointly develop the proposal for a children's specialist behaviour service
- Online research and interviews with commissioners and providers in other areas
- 2 Berkshire Task & Finish Group webinars where Coventry & Warwickshire, Oxfordshire and Hertfordshire shared information about their behavioural support services for children

A needs assessment was undertaken and projected costings / savings for each service development were formulated.

A set of outcomes that the proposals aim to deliver for autistic adults and children or those who have a learning disability and behaviours that challenge, was coproduced and includes:

- More people have their behavioural support needs met locally
- Fewer adults and children are in hospital, and they are only admitted when this is the best therapeutic option
- Fewer children are in residential placements, and only when this is the best option
- Any admission to hospital or residential placement is for the shortest time necessary
- Staff and families have a greater understanding of autism, learning disability and positive behavioural support
- Reduced use of medication and restrictive practices
- Increased multi-agency working
- Earlier intervention to prevent escalation of behaviours
- Greater confidence, knowledge and sense of being supported for family carers
- Improved quality of support in services
- More adults can live in homes they choose, designed for their sensory and behavioural needs, with staff who have the training and skills required
- A growing culture of positive understanding of behaviour, its functions and role in communication is established
- More children with autism or a learning disability are regularly engaging in education
- Improved wellbeing and life chances for children and adults
- Value for money by shifting resources from reactive services to preventative interventions

A list of priority gaps was identified, and proposals were then developed aiming to build on existing provision to create a stronger and more effective pathway of services for this group of people. Nine core proposals were then worked up with a further 6 areas for further development.

#### *Impact of the work to date*

1. A Dynamic Support Register (DSR) for people aged 0-25 is now in place with plans to extend the remit to all ages. It provides oversight of those at risk of admission; co-ordination of multi-agency preventative response and embeds recommendations from Care Education & Treatment Reviews
2. We successfully bid to become a keyworker early adopter site. The keyworker function will be linked to the DSR and the remit will widen over time in line with Dame Lenehan's recommendations. A project manager is in post to co-produce the 0-25 service model. The first keyworkers were expected to be in post from October 2021
3. We have funding to deliver Positive Behaviour Support training across all ages from 2021.
4. There are plans across the Berkshire West, Oxfordshire and Bucks ICS to extend the Intensive Support Team offer from 18+ to all age over the next 3 years.
5. We commissioned some additional non-recurrent resources from the voluntary sector to support families approaching crisis through family support and short breaks

6. Providers are increasingly making adjustments to service offers to make them more “autism and Learning disability friendly”.
7. We have promoted resources to support neurodiverse families and young people with anxiety.
8. A linked piece of work is the all-age crisis review being led by the CCG.

#### 4.2.2 Adults

Adult services have recognised pathways for autistic people with or without a learning disability, to be able to access a care assessment and other support. In the last year, it is unknown how many adults who were assessed as being eligible for adult social care services and who were in receipt of a personal budget, who had a diagnosis of autism.

Autistic adults who could not otherwise meaningfully participate in needs assessments, care and support planning, appeals, reviews, or safeguarding processes have access to an appropriately trained advocate via the local authority’s commissioning of statutory advocacy services. The **Preparing for Adulthood** service has been expanded to help reduce waiting lists for assessments, reviews and social care support.

**Autistic people who are eligible for adult social care support and use direct payments have reported difficulty in finding personal assistants who are able to support their care for reasons including the low hourly pay, the small number of hours of care needed and the limited number of people with appropriate expertise and experience. This can contribute to inadequate support provision for autistic adults and impacts on their carers and availability of short breaks.**

Autistic adults can access support if they are not eligible under the Care Act or not eligible for statutory services. For example, Reading Borough Council commissions **peer support services** for autistic adults. The provider is required to demonstrate that their services improve autistic adults’ access to a range of provisions.

The Mental Health Crisis Service proactively provides assessment support and treatment in the community to those with an autism diagnosis if they are suffering from an acute mental health problem or crisis. Home assessments may be offered too.

There is recognition of the need to improve access to health and care services and develop the local market for community services for autistic people.

#### *Support groups*

There are several 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 of the specific support is in **Table 1. Support groups for autistic children, young people and adults** **Table 1** below – but there are other services within Reading that could be accessed by autistic people.

*Table 1. Support groups for autistic children, young people and adults*

<b>What is available?</b>	<b>What do they do?</b>
<a href="#"><b><u>Berkshire West Autism &amp; ADHD Support Service</u></b></a>	Provided by Autism Berkshire, providing a Helpline, Single Session Therapy, Workshops and Teen Life course, with Parenting Special Children providing the ADHD, Sleep, Transition and Social Interaction groups.
<a href="#"><b><u>Autism Berkshire</u></b></a>	Provider of Berkshire West service as detailed above, including information, advice and guidance for adults, e.g., 197 club peer support group and a Benefits service. Provides an advice and information service about autism, as well as running support groups and training for parents and carers, providing training and support for professionals, and running leisure and social activities for autistic children and adults.
<b><i>Brighter Futures for Children</i></b>	<b>Brighter Futures for Children's Autism Advisor</b> for families in Reading Jenna Redmond runs the ‘Living with Autism’ 6 week programme for parents/carers. Access to this service is through a Children's Single Point of Access The <b>Autism Advisor</b> can be contacted directly by families.

<a href="#"><u>Parenting Special Children</u></a>	Run specialist parenting programmes and support groups for parent/carers who have children with special needs including autism.
<a href="#"><u>Reading Mencap</u></a>	Provide integrated services and support to autistic people and those with learning disabilities and their families. This includes a help line, a home visiting Family Support Service providing information, advice and advocacy, a Day Service and a range of clubs and activities.
<a href="#"><u>Autism Matters</u></a>	Provides training devised and delivered by a qualified, experienced autistic trainer to autistic people, families and professionals. (Private organisation).
<a href="#"><u>The RAFT Club (Reading Autism Families Together)</u></a>	Provides support for families of autistic children living in Reading. RAFT employs 6 DBS checked play workers who organise activities for autistic children and their siblings (4-12+ years). Children aged between 4 and 12 years must have a formal diagnosis of autism or be on the CAMHS pathway.
<a href="#"><u>AutAngel</u></a>	Run by and for the autistic community to empower autistic people, to create opportunities, and help autistic people to reach their full potential. Through various talks and groups including the Exploring Being Autistic programme, Mixed peer support group, Women's peer support group, Craft group, LGBTQ+ support groups, Allotment group, Yoga.
<b>Educational support provision</b>	Children and young people can get help from their schools (in mainstream or specialist education), who can access extra support if that is seen as appropriate for someone's needs. In some cases, this might include support from the Council directly (through the <b>Children &amp; Young People's Disability Team</b> ) or help to access support such as short breaks or holiday clubs.
<a href="#"><u>Adult Social Care</u></a>	The Council's Adult Social Care services may be able to help adults who have difficulty taking care of themselves. This could be information, advice or support provision. Some of these services are for people that meet specific eligibility criteria. People may be asked to contribute towards costs of some support – although the amount paid will depend on their financial situation.

Additional provision for autistic people in Reading/Berkshire includes:

- [Thames Valley Autism Alert Card](#)
- [Autism Friendly Screenings at Showcase Cinemas](#)
- [Autism Berkshire Trampolining](#)
- [Autism Friendly Cinema Screenings Vue Reading](#)

Services providing support to autistic people in Reading have fed back that services are relying on a crisis response for autistic people of all ages. Quality support around education, health (including mental health) and social care have an important role. They emphasise the need for timely, accessible support.

#### 4.3.1 Risk factors and co-occurring conditions

##### *The causes of Autism*

The cause of autism is unknown. Many experts believe that it is likely that there is more than one cause. Some evidence points towards a genetic cause and scientists are trying to discover which genes are involved: autism is likely to have multiple genes responsible rather than one. We do know what **does not** cause autism. Comprehensive research has shown that there is no link between autism and vaccination; it is not caused by emotional deprivation or how a person has been raised.

##### *Co-occurring conditions*

Co-occurring (or comorbid) conditions refers to the occurrence of more than one disorder at the same time. The relationship between the conditions and the factors which cause each condition can work in several different ways. For example, two or more conditions may be caused by the same underlying cause, or the presence of one condition may lead to the development of a second.

Autism is often linked with other conditions. As part of this need's assessment, a literature review of autism and the prevalence of coexisting conditions was conducted by Berkshire Health Library and Knowledge services<sup>22</sup>. The findings from this review are summarised below split by the type of condition: learning difficulties and disabilities, physical difficulties disabilities and disorders, and mental health conditions. Percentages refer to the percentage of autistic people estimated to have each condition. Prevalence refers to current prevalence rather than lifetime prevalence i.e., the proportion of autistic people estimated to have the coexisting condition at any one time.

### *Learning difficulties and disabilities*

Autistic people have a range of intellectual functioning and ability, but many autistic people will also have a learning disability. A learning disability is a lifelong disorder diagnosed in childhood. Around 60-70% of autistic adults have a learning disability<sup>3 4 5</sup> compared to 2.16% of neurotypical people.

**Estimates vary and true prevalence of learning disability amongst autistic people is unclear.** Developmental conditions that tend to co-occur in autistic children and adults include dyspraxia and dyslexia<sup>23</sup>.

Some studies have cited similarities between autism and paediatric traumatic brain injury (TBI). Some recent preclinical and clinical data, indicates TBI and autism share not only similar symptoms and some similar biologic mechanisms that cause these symptoms. However, there is no evidence to suggest that a brain injury can lead to an increased risk of autism.

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<sup>22</sup> Helen Williams. (14 January 2022) Reading, UK: Berkshire Healthcare Library and Knowledge Services.

<sup>23</sup> NHS Choices (2020). Other conditions that affect autistic people. [online] NHS. Available at: <https://www.nhs.uk/conditions/autism/other-conditions/>.

**Table 2. Co-occurring conditions - Physical difficulties and disabilities**

Condition	Description	Percentage of autistic people estimated to have the condition	Reference
<b>Epilepsy</b>	<p>Autistic people are more likely to develop epilepsy than neurotypical people. However, there is no evidence that epilepsy causes autism.</p> <p>Intellectual disability increases the risk of an autistic person developing epilepsy with the risk been as high as 40% for autistic people with severe intellectual disability<sup>24</sup></p>	10-12%	<p>LIU, X., SUN, X., SUN, C., ZOU, M., CHEN, Y., HUANG, J., WU, L. &amp; CHEN, W.-X. 2022. Prevalence of epilepsy in autism spectrum disorders: A systematic review and meta-analysis. <i>Autism: the international journal of research and practice</i>, 26, 33-50</p> <p>LUKMANJI, S., MANJI, S. A., KADHIM, S., SAURO, K. M., WIRRELL, E. C., KWON, C.-S. &amp; JETTÉ, N. 2019. The co-occurrence of epilepsy and autism: A systematic review. <i>Epilepsy &amp; Behavior</i>, 98, 238-248</p>
<b>Sleep problems</b>	<p>Sleep problems are the most common coexisting conditions experienced by autistic people. This may be linked to other coexisting conditions such as gastrointestinal problems and ADHD<sup>25</sup>.</p>	<p>40-80% of autistic children have sleep problems</p> <p>13% diagnosable sleep-wake disorders for all ages</p>	<p>RYDZEWSKA, E., DUNN, K. &amp; COOPER, S.-A. 2021. Umbrella systematic review of systematic reviews and meta-analyses on comorbid physical conditions in people with autism spectrum disorder. <i>British Journal of Psychiatry</i>, 218, 10-19</p> <p>LAI, M.-C., KASSE, C., BESNEY, R., BONATO, S., HULL, L., MANDY, W., SZATMARI, P. &amp; AMEIS, S. H. 2019. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. <i>The lancet. Psychiatry</i>, 6, 819-829</p>
<b>Macrocephaly</b>	<p>A range of neurological disorders have been reported to occur at a greater rate amongst autistic people. Prevalence estimates vary between condition.</p>	13%	<p>PAN, P.-Y., BÖLTE, S., KAUR, P., JAMIL, S. &amp; JONSSON, U. 2021b. Neurological disorders in autism: A systematic review and meta-analysis. <i>Autism: the international journal of research and practice</i>, 25, 812-830</p>
<b>Cerebral palsy</b>		3%	
<b>Migraine/headache (children)</b>		7%	
<b>Congenital nerve system abnormality</b>		4%	
<b>Hydrocephalus</b>		1%	
<b>Gastrointestinal symptoms</b>	<p>Gastrointestinal disorders are one of the most common medical conditions that coexist with autism. Gastrointestinal symptom severity has been shown to</p>	<p>Range from 4% to 31% depending on symptom, with food sensitivities affecting 31% of autistic children compared to 4% of neurotypical children.</p>	<p>CHAIDEZ, V., HANSEN, R.L., HERTZ-PICCIOTTO, I. 2015. Gastrointestinal problems in children with autism, developmental delays or typical development. <i>Journal of Autism and Developmental Disorders</i>, 44, 1117-1127</p>

<sup>24</sup> National Autistic Society (2017). Epilepsy and autism. [online] [www.autism.org.uk](https://www.autism.org.uk/advice-and-guidance/professional-practice/epilepsy-autism). Available at: <https://www.autism.org.uk/advice-and-guidance/professional-practice/epilepsy-autism>.

<sup>25</sup> Pavlopoulou, G. and Dimitriou, D. (2018). Autistic adults and sleep problems. [online] [www.autism.org.uk](https://www.autism.org.uk/advice-and-guidance/professional-practice/sleep-adults). Available at: <https://www.autism.org.uk/advice-and-guidance/professional-practice/sleep-adults>

Condition	Description	Percentage of autistic people estimated to have the condition	Reference
	correlate with the severity of autism-related behaviour <sup>26</sup> .	From 7% to 63% depending on food-related issues, with 63% of autistic children having food dislikes compared to 34% of neurotypical children.	

*Mental health and other conditions*

Condition	Description	Percentage of autistic people estimated to have the condition	Reference
<b>ADHD</b>	Attention Deficit Hyperactivity Disorder (ADHD) is sometimes diagnosed alongside autism with studies indicating that it is one of the most prevalent co-existing conditions in autistic adults.	25-38%	LUGO-MARÍN, J., MAGÁN-MAGANTO, M., RIVERO-SANTANA, A., CUELLAR-POMPA, L., ALVIANI, M., JENARO-RIO, C., DÍEZ, E. & CANAL-BEDIA, R. 2019. Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. <i>Research in Autism Spectrum Disorders</i> , 59, 22-33  RONG, Y., YANG, C.-J., JIN, Y. & WANG, Y. 2021. Prevalence of attention-deficit/hyperactivity disorder in individuals with autism spectrum disorder: A meta-analysis. <i>Research in Autism Spectrum Disorders</i> , 83.  LAI, M.-C., KASSEE, C., BESNEY, R., BONATO, S., HULL, L., MANDY, W., SZATMARI, P. & AMEIS, S. H. 2019. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. <i>The lancet. Psychiatry</i> , 6, 819-829
<b>Anxiety disorders</b>	40% of autistic children, adolescents and adults are thought to have at least one and often more anxiety disorders, with specific phobias and social anxiety among the most common forms.	40%	VAN STEENSEL, F. J. a, BOGELS, S. M., & PERRIN, S. (2011). Anxiety Disorders in Children and Adolescents with Autistic Spectrum Disorders: A Meta-Analysis. <i>Clinical Child and Family Psychology Review</i> , 14(3), 302–317.
<b>Depression</b>	Depression is common in autistic people and can have a big impact on their daily lives	23% of adults  11% of all ages	HOLLOCKS, M. J., LERH, J. W., MAGIATI, I., MEISER-STEDMAN, R. & BRUGHA, T. S. 2019. Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. <i>Psychological Medicine</i> , 49, 559-572.

<sup>26</sup> Hsiao, E.Y. (2014). Gastrointestinal Issues in Autism Spectrum Disorder. *Harvard Review of Psychiatry*, 22(2), pp.104–111.

<b>Condition</b>	<b>Description</b>	<b>Percentage of autistic people estimated to have the condition</b>	<b>Reference</b>
			LAI, M.-C., KASSEE, C., BESNEY, R., BONATO, S., HULL, L., MANDY, W., SZATMARI, P. & AMEIS, S. H. 2019. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. <i>The lancet. Psychiatry</i> , 6, 819-829
<b>Other, less common disorders</b>	Eating disorders	Autistic women are much more likely to develop anorexia than non-autistic women. Most studies have looked at the prevalence of ASD in people with eating disorders; rather than the prevalence of eating disorders amongst autistic people. 1 in 5 women with anorexia are autistic	HUKE, V., TURK, J., SAEIDI, S., KENT, A., & MORGAN, J. F. 2013. Autism spectrum disorders in eating disorder populations: a systematic review. <i>European Eating Disorders Review</i> , 21(5), 345-351
	Emotionally unstable personality disorder (EUPD)/Borderline Personality Disorder (BPD)	4%	MAY, T., PILKINGTON, P. D., YOUNAN, R. & WILLIAMS, K. 2021. Overlap of autism spectrum disorder and borderline personality disorder: A systematic review and meta-analysis. <i>Autism research: official journal of the International Society for Autism Research</i> , 14, 2688-2710
	Post-Traumatic Stress Disorder (PTSD)	PTSD is a mental health condition that can affect anyone. It can develop after a single traumatic event – one that is distressing or stressful. PTSD can also be triggered by repeated trauma such as abuse or bullying. There is some research that suggests that autistic people can develop PTSD symptoms from a wider range of experiences than non-autistic people.	HARUVI, H., HORESH, D. 2020. PTSD and Autism Spectrum Disorder: Co-Morbidity, Gaps in Research, and Potential Shared Mechanisms. <i>Psychological Trauma: Theory, Research, Practice, and Policy</i> , 10(3), 290-299
	Disruptive, impulse-control, and conduct disorder	12%	LAI, M.-C., KASSEE, C., BESNEY, R., BONATO, S., HULL, L., MANDY, W., SZATMARI, P. & AMEIS, S. H. 2019. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. <i>The lancet. Psychiatry</i> , 6, 819-829
	OCD	9%	
	Bi-polar disorders	5%	
Schizophrenia spectrum disorder	4%		

### 4.3.2 Autism inequalities and barriers to support

Compared to non-autistic people, inequalities experienced by autistic people include reduced access to public services and spaces due to challenging sensory environments which can affect wider outcomes. This contributes to existing inequalities such as the gap in employment opportunities<sup>27 28</sup>, poorer health outcomes and life expectancy (a 16-year gap)<sup>29</sup>, increased likelihood to report a lower quality of life<sup>30</sup> and social isolation, which also impacts health<sup>31 32 33</sup>. There are other significant inequalities experienced by autistic people and action to prevent further widening these gaps is vital. One reason thought to contribute to these gaps, particularly in health include challenging communication in inaccessible environments.<sup>34</sup>

As a result of the COVID-19 pandemic, existing challenges experienced by autistic people have been exacerbated such as worsening of mental health conditions including anxiety, avoidable inpatient admissions, loneliness and barriers to accessing public spaces. New challenges have emerged including, understanding social distancing and other COVID safe measures and food shopping challenges. However, this time period has also led to increased awareness and understanding of challenges experienced in people's lives. The pandemic has had a significant impact on many lives, in particular, autistic people and their families, evidenced by the [Left Stranded report](#)<sup>35</sup> and other research findings. There is key local research surrounding loneliness in the '[Tackling Loneliness and Social Isolation in Reading, England](#)' report published in 2019.

#### *Early identification and diagnosis*

Throughout their lives, autistic people experience health and care inequalities which may contribute to their quality of life and life expectancy. To prevent escalation of needs, early identification is a key step in allowing CYP to receive timely support. In Bradford, an early identification pilot programme was developed which involves healthcare and education staff working together to assess children who may be autistic in schools. There have been positive early findings, including enabling children to be identified early and receive timely support. Work is also being undertaken to monitor more closely prevalence of autistic girls as current evidence indicates a higher prevalence of autism in males than females.

NICE guidance recommends 13 weeks between referral and first assessment. Current experimental Autism Waiting Times statistics show that nationally, most people wait much longer than the 13 week period which is echoed locally<sup>21</sup> *NB: Waiting times based on reporting of diagnoses by community services where children are usually diagnosed are not always reported.*

#### *Health and Care*

Early autism diagnosis is important as well as diagnosis of health problems amongst autistic people, evidenced to be challenging. Challenges arise from various factors including, likelihood

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<sup>27</sup> Office for National Statistics (2021). Outcomes for disabled people in the UK - Office for National Statistics. [online] [www.ons.gov.uk](https://www.ons.gov.uk). Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020>.

<sup>28</sup> Allen M & Coney K (2018). What Happens Next? 2018: A report on the first destinations of 2016 disabled graduates. The Association of Graduate Careers Advisory Services.

<sup>29</sup> Bishop-Fitzpatrick, L., & Kind, A. (2017). A Scoping Review of Health Disparities in Autism Spectrum Disorder. *Journal of autism and developmental disorders*, 47(11), 3380–3391. <https://doi.org/10.1007/s10803-017-3251-9>

<sup>30</sup> Mason D, et al. (2018) Predictors of Quality of Life for Autistic Adults. *Autism Res* 11(8), 1138-1147.

<sup>31</sup> Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, [online] 208(3), pp.232–238. Available at: <https://pdfs.semanticscholar.org/d4ca/e0b1efaaaf1e6d4ad452636ea6a898bb7e67.pdf>.

<sup>32</sup> Ryzewska, E, et al. (2019) General health of adults with autism spectrum disorders – A whole country population cross-sectional study. *Research in Autism Spectrum Disorders* 60, 59-66.

<sup>33</sup> Westminster Commission on Autism (2016). *A Spectrum of Obstacles: An inquiry into access to healthcare for autistic people.*

<sup>34</sup> Raymaker D. et al. (2017) Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism* 21(8), 972-984.

<sup>35</sup> National Autistic Society (2020a). *Left stranded: The impact of coronavirus on autistic people and their families in the UK.* [online] Available at: <https://pearsfoundation.org.uk/wp-content/uploads/Left-Stranded-Report-Autism-Covid-2020.pdf> [Accessed Jan. 2021].



of co-occurring conditions (e.g., allergies, gastro-intestinal disorders, autoimmune conditions, diabetes, heart disease and Parkinson's disease etc),<sup>32</sup> a lack of autism understanding by health and care professionals, resulting in adjustments to support engagement in health appointments being missed. This can have a knock-on effect, by overlooking, misunderstanding, or disregarding indicators of illness until autistic people's needs have worsened, causing distressing experiences and resulting in poor health outcomes.<sup>34 36</sup> This additionally results in delay or avoidance of seeking medical support.

Some barriers experienced by autistic people include reduced likelihood to understand signs of poor-health and barriers to NHS service access when needed e.g. from uncertainty which brings on anxiety and miscommunication, sensory variances, different responses to pain and alexithymia (difficulty identifying own emotions)<sup>29 33 37 38 39</sup>

To ensure that autistic people receive appropriate healthcare support in the appropriate way, adjustments must be made, but it is not always possible nor easy for professionals to identify autistic people and adjustments required. So training is required and resources to support this identification, using existing systems or implementation new systems where possible.

Early identification, improvements in diagnostic pathways for all ages and reductions in waiting times for diagnosis are key in order to ensure quick diagnosis and appropriate access to support at the right time. This also enables autistic people and those supporting them to better understand their needs.

Although diagnosis rates for adults have improved, and more adults are diagnosed as autistic, waiting times for diagnosis are very long for many, worse than previous years and exceeding the 13-week NICE recommended times. Many contributory factors exacerbate the long waiting times, such as growing waiting lists resulting from increasing autism public awareness leading to increased referrals, as such, increasing demand on services. This has been further compounded by the COVID-19 pandemic, halting or slowing down some local assessment systems. Longer waits can also be a result of delays or obstructions in the diagnostic pathways resulting from workforce pressures and diagnostic models used.

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, as evidenced by the National Autistic Society. It is well known that autism diagnosis as early in life as possible is vital so that children receive the appropriate support needed, especially as part of the transition into adulthood.

Work needs to be done to facilitate early identification of autistic people's needs, enabling improved mental and physical health. This can be done through piloting of hearing, sight and dental checks for children in special residential schools and Autism Health Checks (HCs) as committed to by the NHS Long Term Plan<sup>18</sup>, and being trialled in the North of England.

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<sup>36</sup> Nicolaidis, C., Raymaker, D.M., Ashkenazy, E., McDonald, K.E., Dern, S., Baggs, A.E., Kapp, S.K., Weiner, M. and Boisclair, W.C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, [online] 19(7)

<sup>37</sup> Nicolaidis C, et al (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. *J Gen Intern Med.* 28(6), 761-9.

<sup>38</sup> Sagr Y, et al. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism* 22(1), 51-62

<sup>39</sup> Liptak G, et al (2006). Satisfaction with primary health care received by families of children with developmental disabilities. *J Pediatr Health Care* 20(4), 245-52.

Autistic people are more likely to die early from a range of factors such as suicide, cardiovascular disease and mental health problems.<sup>40</sup> Evidence indicates it is more likely for autistic people to require hospital care or use emergency services than non-autistic people.<sup>41 42</sup>

Currently, at-risk groups and people with learning disabilities are offered HCs. HCs can be used to proactively target support at people experiencing health inequalities and targeted Autism HCs may enable GPs to enhance their autism knowledge, increase accessibility and enable systematic and person-centre care for autistic patients while opening up a clear pathway for service access and contribute to improved health outcomes. Autism HCs could possibly help reduce the need for access to tertiary services and be a cost-effective option.

Improving health and care staff's understanding of autism is crucial in enabling progress on reducing health inequalities for autistic people.

A key role in recognising autistic people's support needs during their life is played by Social Workers. As such, consistent training and support for all Social Workers working with autistic people is recommended throughout Reading. New National Assessment and Accreditation System (NAAS) simulated practice and knowledge assessment materials for social workers will be available. This is alongside the offer of Oliver McGowan Mandatory Training and publishing of a Capability Statement for social work with autistic children and their families consistent with the current Capability Statement for Social Work with Autistic Adults so that they have the essential knowledge to support them throughout their lives including providing reasonable adjustments for autistic people, contributing to tackling health and care inequalities they experienced.

### *Post-diagnostic support*

An NHS Long Term Plan key priority includes addressing health inequalities. Effective follow-up after diagnosis supports this and facilitates identification of health inequalities. Post-diagnostic support could help autistic people be more actively involved in their community and the economy.<sup>43</sup>

### *Gender disparities*

There is a gender gap in the prevalence of autism, with higher prevalence in males than females (ratio of 3:1). It is suspected that this may be the result of underdiagnosis of autism in females.<sup>44</sup> Autistic women often report being dismissed due to misconceptions and biased assessments by professionals due to females reportedly presenting autistic traits differently to boys.

Recent research shows that the gender gap has been closing with smaller differences in autistic men and women<sup>44</sup>. Overall, evidence suggests that autistic women are more likely to grow up undiagnosed, thus have later diagnoses<sup>45</sup> and those without learning disabilities are more likely to be missed. Autistic females are less likely to receive a diagnosis compared males with comparable autistic traits.<sup>46</sup> It is suggested that unless autistic females have additional difficulties, they will likely be missed, potentially due to biased application of assessment tools or their design.<sup>47 48</sup> Autistic females are likely to be misdiagnosed with

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<sup>40</sup> Bishop-Fitzpatrick L, et al. (2018). Using machine learning to identify patterns of lifetime health problems in decedents with autism spectrum disorder *Autism Research* 11(8).

<sup>41</sup> Zerbo O et al. (2018) Healthcare Service Utilization and Cost Among Adults with Autism Spectrum Disorders in a U.S. Integrated Healthcare System. *Autism in Adulthood*.

<sup>42</sup> Hand B. et al. (2018) Ambulatory Care Sensitive Admissions in Individuals with Autism Spectrum Disorder, Intellectual Disability, and Population Controls. *Autism Research*.

<sup>43</sup> Buescher A, et al. (2014) Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatrics* 168(8), 721-728.

<sup>44</sup> Rutherford M, et al. (2016) Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism* 20(5), 628-34.

<sup>45</sup> Brett D, et al. (2016) Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014. *J Autism Dev Disord* 46, 1974-1984

<sup>46</sup> Russell G, et al. (2011) Social and demographic factors that influence the diagnosis of autistic spectrum disorders. *Soc Psychiatry Psychiatr Epidemiol* 46(12), 1283-93

<sup>47</sup> Adamou M, et al. (2018) Autism Diagnostic Observation Schedule (ADOS) scores in males and females diagnosed with autism: a naturalistic study. *Advances in Autism* 4(2), 49-55.

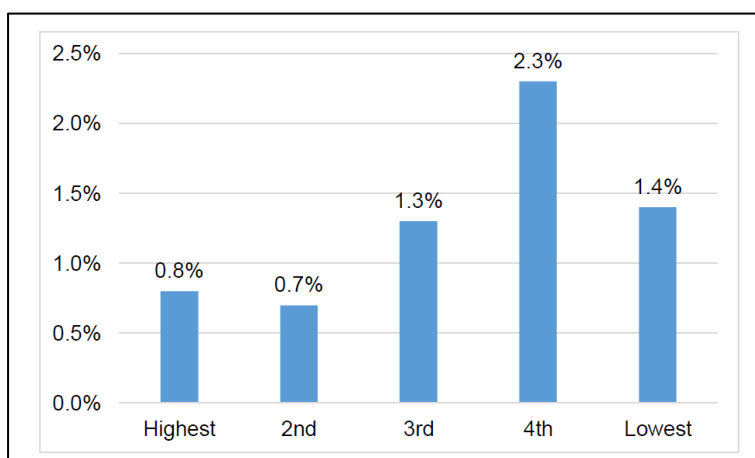
<sup>48</sup> Rogers CL, et al. (2016) Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom. *Autism* 20(7), 820-31.

mental health conditions<sup>49</sup>. Autistic females with a learning disability are some of the most at risk of premature death in the autistic community including higher risk of dying by suicide compared to non-autistic women. Other inequalities include being at greater risk of abuse<sup>50</sup> and reporting lower quality of life compared to their male counterparts<sup>30 31</sup>.

### Socio-economic status

Associations between health and wellbeing and unemployment are recognised<sup>51</sup> and high rates of unemployment in autistic people could therefore widen health inequalities e.g., unemployment is a risk factor for suicide<sup>32</sup> amongst autistic people, known to be a leading cause of premature death. Employment improves productivity, increases independence and benefits autistic people's wellbeing and quality of life.<sup>43</sup>

Evidence suggests an association between living in a low-income household and autistic children as reported by the NHS Digital report from the Mental Health of Children and Young People Survey, 2017<sup>52</sup> (see **Figure 19**).



**Figure 19. Autism prevalence in 5-19 years olds by household income quintile. Source: NHS Digital<sup>52</sup>**

There appear to be mixed findings in relation to the association between socioeconomic status and autism with some studies reporting a link between higher socioeconomic status and autism. However, it is suspected that this may be due to higher case detection in those from higher socioeconomic backgrounds rather than a direct relationship.

In comparison to children of mothers with lower education attainment (0.7%), higher autism diagnosis rates (1.5%) were reported in children with mothers with higher educational attainment levels, by a study using Born in Bradford cohort data made up of 13,857 children who were born between 2007-2011.<sup>53</sup> There was no significant association seen between autism prevalence, income nor neighbourhood deprivation level once maternal education level was taken into account. This was supported by similar findings in another UK based study of 9-10 years olds<sup>54</sup>. Findings suggest that autism may be under-diagnosed in children of parents with lower education attainment.

<sup>49</sup> Takara K, et al. (2015) How and Why is Autism Spectrum Disorder Misdiagnosed in Adult Patients? From Diagnostic Problem to Management for Adjustment. *Mental Health in Family Medicine* 11, 73-88.

<sup>50</sup> Sedgewick F, et al. (2019) Friends and Lovers: The Relationships of Autistic and Neurotypical Women. *Autism in Adulthood* 1(2), 112-123

<sup>51</sup> Dorling D (2009). Unemployment and health. *BMJ* 333:b829.

<sup>52</sup> NHS Digital (2018). Mental Health of Children and Young People in England, 2017 [PAS] - NHS Digital [online]. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>.

<sup>53</sup> Kelly, B., Williams, S., Collins, S., Mushtaq, F., Mon-Williams, M., Wright, B., Mason, D. and Wright, J. (2017). The association between socioeconomic status and autism diagnosis in the United Kingdom for children aged 5–8 years of age: Findings from the Born in Bradford cohort. *Autism*, 23(1), pp.131–140.

<sup>54</sup> Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531), pp.210–215.

It is thought that if the association between lower socioeconomic status and autism is accurate, it is expected that the underlying mechanisms are multifaceted. More recent studies looking at treatment and service use disparities experienced by autistic people report that children from low-income families and ethnic minority groups have lower quality of care, reduced access to educational services, specialized services, acute care and community services compared with higher-income and Caucasian families.<sup>55</sup> Earlier evidence revealed similar findings around racial, ethnic, and socioeconomic disparities associated with autism and that these are apparent throughout many service areas including access to early assessment, diagnosis, and therapeutic interventions. Identified themes reported as contributing to autism disparities included cultural, structural and familial barriers<sup>56</sup>

The evidence of the association between socioeconomic status and autism varies, however it is suspected that 'detection bias' relating to socioeconomic status skews findings as diagnosis may be less likely in children from lower socioeconomic status households and with parents with lower educational attainment levels.

### *Mental Health*

Autistic people are more likely to experience a range of mental health conditions (see co-occurring conditions chapter) however, some traits of autism can also be confused with symptoms of mental ill-health and diagnostic tools may not always account for these differences.<sup>57</sup>

### *Race and ethnicity*

A recent study reported that young autistic ethnic minority groups from lower income backgrounds were less likely to receive health care transition services, participate in social activities, 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. In relation to educational, occupational, and social activities, autistic ethnic minority and low-income young people were more likely to be disconnected upon entering adulthood.<sup>58</sup>

Similar ethnic disparities were found in North America surrounding autism diagnosis. Other research indicated similar autism prevalence rates in immigrant children as native children, however, that diagnosis occurred later in comparison to native children. A separate study found higher autism prevalence (2.2) and lower prevalence of Asperger syndrome in immigrants (0.6) while another reported a lower prevalence of Asperger syndrome in immigrants (0.1). Most analyses included immigrants from outside Europe, e.g., Africa and South America. European conducted studies bring uncertainty in relation to whether higher autism prevalence estimates among immigrants in Europe reflect true variances, particularly considering various potential confounding factors, including environmental, biological, genetic, and cultural. Further research on autism prevalence rates in immigrant groups is needed which considers the number of people migrating within Europe.<sup>59</sup> Research indicates that racial, ethnic, and socioeconomic disparities associated with autism exist throughout many service areas including access to early assessment, diagnosis, and therapeutic interventions. Cultural, structural and familial barriers were identified as interdependent themes contributing to autism disparities.<sup>56</sup>

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<sup>55</sup> Smith, K.A., Gehricke, Jean-G., Iadarola, S., Wolfe, A. and Kuhlthau, K.A. (2020). Disparities in Service Use Among Children with Autism: A Systematic Review. *Pediatrics*, 145(Supplement 1), pp.S35–S46.

<sup>56</sup> Singh, J.S. and Bunyak, G. (2018). Autism Disparities: A Systematic Review and Meta-Ethnography of Qualitative Research. *Qualitative Health Research*, 29(6), 796-808

<sup>57</sup> Wigham S, et al. (2018) Psychometric properties of questionnaires and diagnostic measures for autism spectrum disorders in adults: A systematic review. *Autism*.

<sup>58</sup> Eilenberg, J.S., Paff, M., Harrison, A.J. and Long, K.A. (2019). Disparities Based on Race, Ethnicity, and Socioeconomic Status Over the Transition to Adulthood Among Adolescents and Young Adults on the Autism Spectrum: a Systematic Review. *Current Psychiatry Reports*, 21(5).

<sup>59</sup> Kawa, R., Saemundsen, E., Lóa Jónsdóttir, S., Hellendoorn, A., Lemcke, S., Canal-Bedia, R., García-Primo, P. and Moilanen, I. (2016). European studies on prevalence and risk of autism spectrum disorders according to immigrant status—a review. *The European Journal of Public Health*, 27, 101-110.

#### 4.3.2.1 Ethnic minority groups and seldomly heard groups in Reading

Services supporting local autistic people in Reading have reported that those who have English as a second language or are from some ethnic minority groups experience disparities in accessing support services and, as a result, are less frequently known to social care services. In addition, some services have reported that Black autistic young people that they support have reported that they feel they are more frequently and unfairly stopped by police and that this causes distress and anxiety that makes them less likely to leave their homes.

#### 4.3.3 Recommendations

- Work on promoting local autism groups
- Raising awareness of existing pre and post diagnostic support provision and making it clear and easy to find, which will aid in proactive identification of people awaiting diagnosis, crisis prevention and prevention of avoidable admissions into inpatient mental health settings.
- Implement an early identification pilot involving healthcare and education staff working together to assess children who may be autistic in schools could be applied in Reading.
- Ongoing improvement of health and care staff and education staff's understanding of autism and identification skills to help in ensure appropriate adjustments are made and programmes developed to improve the health of autistic people and address some of the inequalities faced by autistic people e.g., through Autism Health Checks.
- Implementation of Oliver McGowan Mandatory Training on learning disabilities and autism for all health and care staff
- Improve commissioners' and social workers' understanding and capability to develop the appropriate services and support provision required by autistic people.
- Autism needs to be prioritised by leadership in local health systems and recognition of commitments set out in the NHS Long-term Plan, the Mental Health and Wellbeing Recovery Action Plan and aligned with other priorities within the Berkshire West Joint Health and Wellbeing Strategy and associated Implementation Plans.
- Inclusion of Autism and Learning Disability Champions in every Integrated Care Partnership to implement accessible and quality autism and learning disability services.
- All Integrated Care Boards, to focus on autism and learning disabilities at the highest level and have a named executive lead for autism and learning disability as recommended by the national all age autism strategy.
- Service providers to work with Thames Valley Police to better document hate crimes and offer autism awareness training in order to better understand and support autistic people.

#### 4.3.4 Autism associated costs

Autism associated costs vary and can include unemployment or disrupted employment of autistic people and their families equating to lost productivity, private residential or hospital accommodation costs and supported living. There are more direct costs such as medical costs, care services including, day care, after school care and special education. Additional costs can arise including modifications to homes and medical appointment travel costs.

The estimated annual and lifetime costs of autism in the United Kingdom and the USA, have been evidenced by Buescher et al. (2014)<sup>43</sup> and cited by NICE<sup>60</sup>. Analysed costs included special education, medical services, non-medical services, employment support, accommodation, and out-of-pocket payments by families.

It was estimated that approximately £3.1 billion annually, was the cost of autistic children below the age of 18 (UK). A prevalence of 40% was assumed of intellectual disability (ID - IQ below 70). At an assumption of 60% ID, the estimated annual cost was £3.4 billion. A life expectancy of 67 years for autistic people was used to estimate lifetime costs. For autistic children, loss of

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<sup>60</sup> NICE (2015). Eyes on Evidence. Expert commentary on important new evidence. Costs of autism spectrum disorders.

parental productivity, indirect non-medical costs and direct non-medical costs including special education were the main drivers of the costs mentioned.

Direct medical costs, accommodation and loss of productivity for autistic people were identified as the biggest factors contributing to the annual costs for autistic adults, estimated at £29 billion with an assumed 40% prevalence of ID and £31 billion at a higher prevalence of 60% (UK).

For those considered to have ID, the estimated cost across the lifespan of an autistic person (UK) was £1.5 million a person, while for those without ID the cost was £0.92 million.

There are limitations to the analyses made including estimation by imputation\* for some data and the problematic routine monitoring and aggregation of costs associated with autism. Additionally, the potential advantages of support and interventions were not considered and the proportion of autistic people with IDs may have been exaggerated which could result in overestimated calculated costs. Even with these limitations, this research represents the most accurate estimations according to NICE and overall, evidence shows the costly nature of autism, for society and for families of autistic people. This is further increased directly and indirectly, where autistic people also have an ID, even more so if this includes impaired life skills development. A more recent systematic review<sup>61</sup> of evidence scoping various countries (US, UK, Australia, Canada, Sweden, the Netherlands) highlighted similar findings regarding the economic costs of autism, with most costs associated with:

- Medical, healthcare service and Therapeutic costs
- (Special) education costs; Costs of production loss for autistic adults
- Informal care costs and lost productivity for family/caregivers
- Accommodation, respite care costs and out-of-pocket expenses.

The overall finding was that autistic people and families with autistic CYP have higher costs, with education appearing to be the costliest aspect for parents.

Life expectancy overall, has been increasing over the years. Although autistic people have a lower life expectancy than non-autistic people, they are living longer than before. Though positive, it comes with an implication around the need for services that support autistic person while supporting their age-related needs. Further work needs to be done to ascertain the growing needs of an aging autistic population which may require more tailored services.

To support commissioners and improve their ability to provide appropriate support services for autistic people, there will be a national rollout of a qualification for commissioners working with people with learning disabilities and autistic people, which is targeted at 120 NHS and Local Authority commissioners. This has been developed by the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA) and Skills for Care. Guidance has also been developed by the National Development Team for Inclusion (NDTi) and Skills for Care to assist commissioners develop appropriate services for autistic people as a result of recognising local demand.

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<sup>61</sup> Rogge, N. and Janssen, J. (2019). The Economic Costs of Autism Spectrum Disorder: a Literature Review. *Journal of Autism and Developmental Disorders*, 49(7).

## 5 | Prevalence

### 5.1 Understanding Prevalence

Prevalence refers to the number of people in a specific location and time who have a condition or characteristic. It is usually shown as a percentage, or rate of the total number of people in that same location and time. We need to know how many autistic people and children there are in Reading and who require services in order that we plan these services appropriately. However, we do not have a direct count of all autistic people and children in Reading, as not all will have a diagnosis so this information will not be recorded. To address this, we use prevalence estimates which have come from robust national studies alongside what we know from local service data. Data from these national studies are presented under 'national prevalence' below and these have been used to give a sense of the total number of autistic people and children in Reading. However, it is acknowledged that the needs of autistic adults and children are wide-ranging with some needing no, or little, support whilst others may need high levels of care.

### 5.2 National Prevalence

The overall prevalence of autism in the UK population age 5 years and over is 1.1%<sup>52 62 63</sup>. This equates to roughly 700,000 adults and children and, if you include their families and carers, autism is part of daily life for 3.7 million people<sup>1</sup>.

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

#### 5.2.1 Adult prevalence

The above adult prevalence estimates are based on the combined results of two studies: The [2007 Adult Psychiatric Morbidity Survey \(APMS 2007\)](#) and an extension of the study looking at [adults with learning disabilities](#). Adult prevalence in the first study alone was found to be 1%. The prevalence of autism was found to be higher in men (2%) than women (0.3%). The follow-up study was used to extend the findings of the original study as people with learning disabilities were not covered by the APMS. The prevalence of autism among adults with learning disabilities living in private households was found to be 35%. Among adults with learning disabilities living in communal care establishments the prevalence was 31%. Prevalence of autism increased with greater severity of learning disability/lower verbal IQ. Prevalence estimates based on the two studies are summarised by gender in the chart below.

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<sup>62</sup> NHS Digital (2012). Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults/estimating-the-prevalence-of-autism-spectrum-conditions-in-adults-extending-the-2007-adult-psychiatric-morbidity-survey>.

<sup>63</sup> NHS Digital (2017). Mental Health of Children and Young People in England, 2017. Autism spectrum, eating and other less common disorders.

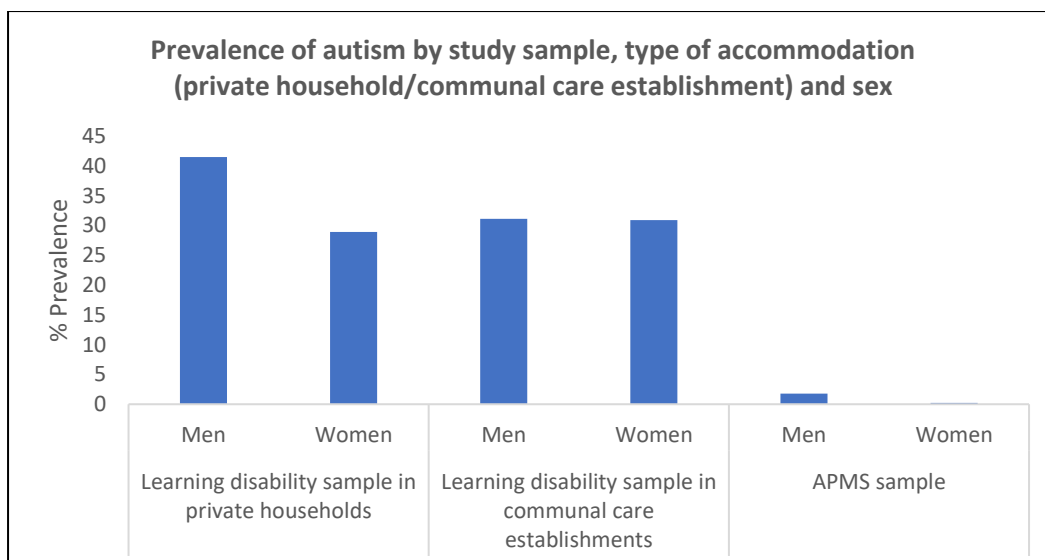


Figure 20: Adult Autism Prevalence <sup>62</sup>

### [Estimating the Prevalence of Autism Spectrum Conditions in Adults](#)

#### 5.2.2 Childhood prevalence

As well as the APMS, NHS Digital conduct a large-scale survey of the mental health of children and young people aged 5 to 19 in England. Surveys were conducted in 1999, 2004, and 2017. However, it should be noted that due to the relatively small numbers of autistic children identified in the sample, associated prevalence estimates will lack precision. The overall prevalence of autism in the 2017 study was 1.2%. Similarly, to the adult study, autism was found to be more common in boys (1.9%) than girls (0.4%). Those with recognised special educational needs were more likely to have autism (13.9% compared to 0.1% of those without special educational needs). It is very likely that the special educational need is related to autism, but this was not investigated as part of the study. Autistic children were found to be more likely to live in lower income households and with a parent in receipt of benefits.

There was no evidence found in the study to suggest that rates of autism had increased since 2004. Rates of autism were found to be higher in the younger age groups, but this was not found to be a statistically significant difference and there were limitations of the study that reduce the reliability of age group comparisons. These include the lack of parental reports and the fact that no teacher reports were obtained for the older age groups leading to potential under-identification.

White British children were about three times more likely to have autism. However, research on variation by ethnic group is mixed, and migration status may compound the relationship<sup>64</sup>. The higher rate of diagnosis of autism amongst White British children has also been thought to be related to greater identification and service access.

<sup>64</sup> Becerra, T.A., von Ehrenstein, O.S., Heck, J.E., Olsen, J., Arah, O.A., Jeste, S.S., Rodriguez, M. and Ritz, B. (2014). Autism Spectrum Disorders and Race, Ethnicity, and Nativity: A Population-Based Study. PEDIATRICS, [online] 134(1), pp.e63–e71. Available at: <http://pediatrics.aappublications.org/content/134/1/e63>.



**Table 3: Summary of estimated National Autism prevalence**

<b>Population group</b>	<b>Estimated Autism prevalence</b>
Adult males	2%
Adult females	0.3%
Adult males – no learning disability	1.8%
Adult females – no learning disability	0.2%
Adult males – with a learning disability	36.3%
Adult females – with a learning disability	29.9%
Boys	1.9%
Girls	0.4%
Children with special educational needs	13.9%
Children with no special educational needs	0.1%

[Estimating the Prevalence of Autism Spectrum Conditions in Adults/Mental Health of Children and Young People, 2017](#)<sup>62</sup>

## 5.3 Local Prevalence

### 5.3.1 Estimated numbers of autistic people in Reading

If we were to apply the overall adult and child gender-specific prevalence estimates given above to the local Reading population then the numbers of autistic adults and children would be estimated to be as per the table below.

It is important to note that, whilst indicative, these estimates do not consider anything in the Reading population that may influence the number of autistic people living in an area other than age and gender. They should be read alongside the other information contained within this report, specifically the rates of autistic people living in Reading who are known to services as compared to the national averages. If there is a discrepancy between the local rates known to services and national averages, in the absence of evidence that this may be due to increased identification, then this could indicate that the overall number of autistic children and adults living in Reading is higher or lower than national prevalence estimates would suggest.

**It should also be noted that estimated prevalence of 0.3% in females is now considered to be an underestimate and to reflect under-diagnosis in women and girls (see gender disparities section above).**

**Table 4: Estimated number of autistic adults and children in Reading**

	<b>National Prevalence</b>	<b>Reading Population</b>	<b>Reading Estimated number</b>
Males aged 18+	2.0%	62,467	1,249
Females aged 18+	0.3%	60,616	182
<b>Total aged 18+</b>	<b>1.1%</b>	<b>123,083</b>	<b>1,354</b>
Boys aged 5-10	2.5%	6,761	168
Boys aged 11-16	1.8%	5,887	104
Boys aged 17-19	1.0%	2,864	27
Girls aged 5-10	0.4%	6,390	25
Girls aged 11-16	0.7%	4,669	31
Girls aged 17-19	-	2,870	-
<b>Total aged 5-19</b>	<b>1.2%</b>	<b>29,441</b>	<b>353</b>

*NHS Digital Mental Health Prevalence Survey Estimates applied to Office for National Statistics mid-2020 population estimates*

### 5.3.2 Autistic people estimated to be accessing services and support in Reading

Estimates of local prevalence are commonly made based using the results of national surveys modelled against local population estimates. In the table below estimates for Reading for adults and children have been compared to what we know about the number of autistic people accessing services and support in Reading.

Calculating the number known to services is not straightforward. Many services do not collect information about autism and many of those that do usually only collect information if the person meets set eligibility criteria for a service or support. Even where the information is routinely collected, there may be differences in coding, recording and data quality between organisations and teams.

From the opposite perspective, prevalence estimates may disguise local variations related to differences in age, ethnicity and gender in the population, patterns of affluence and deprivation and exposure to services and professionals that can help to identify and prompt diagnosis. Awareness of autism and knowledge about its epidemiology and aetiology are still growing, so it is not always clear which factors may affect prevalence. As a result, the estimated number could be very different to the true number of autistic people in the local population.

Nonetheless, comparing estimates with the number of autistic people that are known to engage with services can help to tell us more about the number of autistic people in Reading and the number of autistic people who may not have had their autism identified or diagnosed and may not therefore have access to support that would enable them to live full and healthy lives.

*Table 5. Estimated prevalence and estimated numbers known to services*

	Reading Estimated number	Estimated numbers known to service	Service/ source data
<b>Adults (18+)</b>	<b>1,354</b>	<p><b>160</b> adults with autism (including Asperger's) in snapshot of Adult Social Care at the start of 2022 (adults who met eligibility criteria for a social care service)</p> <p><b>329</b> coded with diagnosis of Autism Spectrum Disorder (John Hopkins ACG coding) in snapshot of primary care data at the start of 2022</p>	<p><i>Health services (Connected Care/Frimley ICS Insights Dashboard)</i></p> <p><i>Adult social care</i></p>
<b>Children and young people aged 5-19</b>	<b>353</b>	<p><b>520</b> children had an EHCPs with ASD identified as the primary need.</p> <p><b>159</b> children aged 5-16+ years were known to children's social care in 2021 (children who met eligibility criteria for a social care service).</p> <p><b>644</b> coded with diagnosis of Autism Spectrum Disorder (John Hopkins ACG coding) in snapshot of primary care data at the start of 2022</p>	<p><i>Schools</i></p> <p><i>Children's social care</i></p> <p><i>Health services (Connected Care/Frimley ICS Insights Dashboard)</i></p>

### 5.3.3 Estimated number not known to services

The number of autistic children and young people in Reading appears higher than modelled estimates. As described above, our knowledge about epidemiology and aetiology of autism is likely to be incomplete, but there may be several wider determinants that lead to variations in prevalence across different communities. There is no clear explanation for this difference in Reading, but it may be useful to consider the following:

- Effects of patterns of affluence and deprivation – for example, families with autistic children may have needs that may require additional resources to meet effectively, which may affect their income, parental employment and other factors.
- Levels of awareness of autism in schools and other services working with children and young people.
- Accessibility of services that may support with identification, accessing diagnosis and other support.

Although the known number of autistic children known to schools and other services in Reading exceeds modelled prevalence, the number of autistic adults recognised in primary care and social care is lower than predicted. This may reflect a relative lack of opportunity to identify autism in adults compared to children attending school. It should be acknowledged that, although knowledge and awareness about autism has improved in the last 20-30 years, autism may not previously have been reliably identified and diagnosed in children. By narrower age group, the largest number of autistic adults not diagnosed or engaged with primary care or support are likely to be aged 35-64. Very few older autistic adults were known to services. Less than 5% of the modelled estimated number of autistic adults aged 55 or older were identified, suggesting that most in these age groups may not be aware they are autistic or have not been diagnosed.

*Table 6. Estimated number of autistic adults in Reading by narrow age groups (using ONS population estimates 2020) compared to number of Reading residents diagnosed with ASD recorded in primary care data (snapshot from March 2022)*

Age group	Estimated number	Number recorded in primary care data	Difference
18-24	193	151	42
25-34	272	152	120
35-44	244	42	202
45-54	209	42	167
55-64	163	16	147
65-74	105	x	105
75+	87	0	87

Source: PANSI/POPPI and Connected Care (Frimley ICS) (number under 10 suppressed)

## 5.4 Projections of future need

### 5.4.1 Adults

The Institute of Public Care publishes forecasts of demand for future social care services. Projections are based on studies of prevalence and modelled using population projections published by the Office for National Statistics (ONS). The information about the number of autistic adults is based on Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 and was published by the Health and Social Care Information Centre in September 2009. The prevalence of ASD was found to be 1.0% of the adult population in England, using the threshold of a score of 10 on the Autism Diagnostic Observation Schedule to indicate a positive case.

**Table 7. People aged 18-64 predicted to have autistic spectrum disorders projected to 2024**

Age group	Number of people predicted to have autistic spectrum disorders in Reading				
	2020	2025	2030	2035	2040
18-24	193	205	231	235	217
25-34	272	265	257	270	292
35-44	244	227	218	214	206
45-54	209	207	201	193	186
55-64	163	176	176	176	172
Total population aged 18-64 predicted to have autistic spectrum disorders	1,081	1,080	1,083	1,088	1,073

Source: [Projecting Adult Needs and Service Information](#)

**Table 8. People aged 65+ predicted to have autistic spectrum disorders, by age and gender, Reading, projected to 2024**

Age group	Number of people predicted to have autistic spectrum disorders in Reading				
	2020	2025	2030	2035	2040
65-74	105	113	129	139	141
75+	87	97	105	119	136
Total population aged 65+ predicted to have autistic spectrum disorders	192	210	234	258	277

Source: POPPI

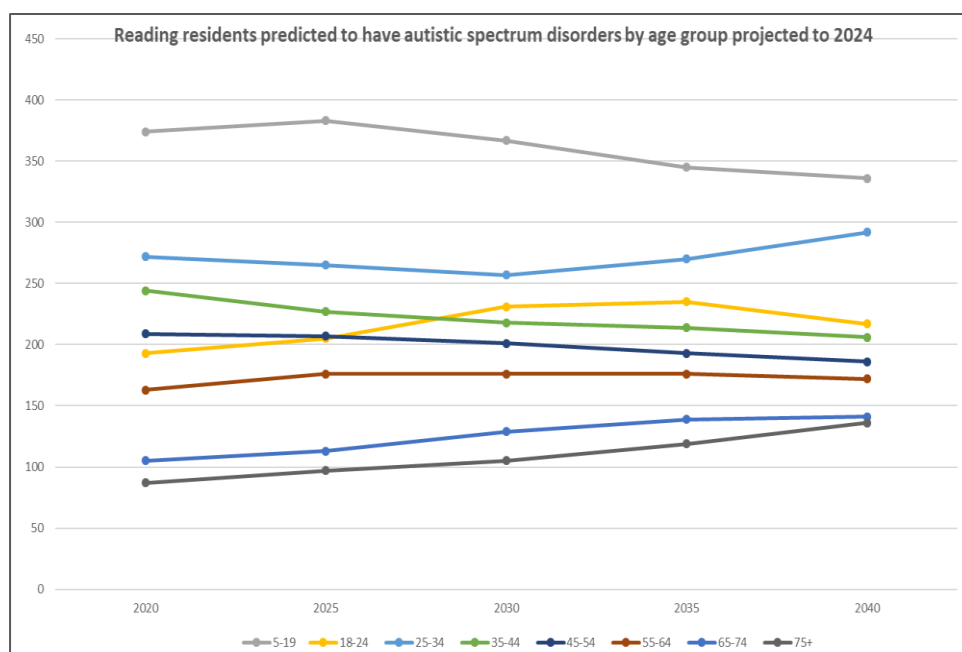
### 5.4.2 Children and young people

This methodology can be replicated using prevalence estimates and population projections as follows. Please note that the most recent population projections are based on 2018 population estimates, so may differ slightly from estimates based on 2020 population estimates.

**Table 9. Number of children and young people predicted to have autistic spectrum disorders in Reading**

Age group	Number of children and young people predicted to have autistic spectrum disorders in Reading				
	2020	2025	2030	2035	2040
Children and young people aged 5-19	374	383	367	345	336

Source: NHS Digital Mental Health Prevalence Survey Estimates applied to Office for National Statistics ONS population projections (2018-based)



**Figure 21. Reading residents predicted to have autism by age group projected to 2024**

These predictions suggest that the number of autistic children and young people seems likely to continue to increase until 2025 and then decline. They suggest a corresponding increase in 18-24 year olds from 2025 and in 25-34 year olds from 2030.

The number of autistic people aged 65 and older is predicted to increase by 44% between 2020 and 2040.

## 6 | Local Services

### 6.1 Children

#### 6.1.1 Social care

##### *How social care services support autistic children and young people*

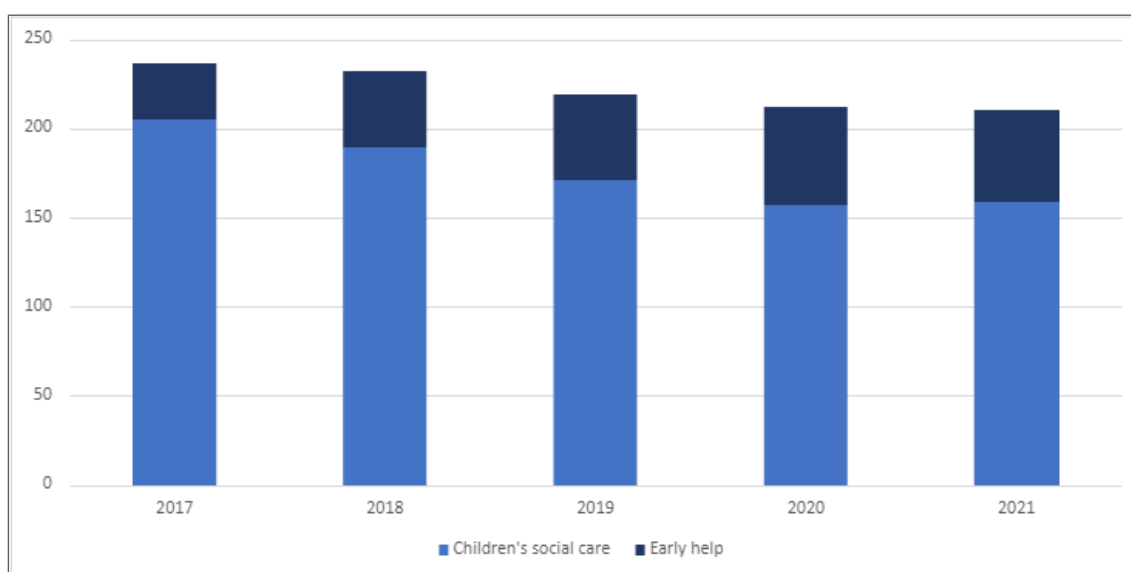
Local authorities have a duty to assess and fund services to meet the needs of children under 18 and to assess the needs and wellbeing of their parent carers (section 17 of the Children’s Act and Children and Families Act 2014).

Following an assessment of need, social care services could provide autistic children with a range of practical support to enhance their emotional wellbeing; improve educational attainment and engagement and ensure their safety. This may include support with day-to-day activities, taking part in recreational or social activities or with equipment. Families may be able to access short breaks from caring responsibilities and assessment should consider whether carers have suitable personal, social, emotional and practical support in their caring role and whether they are likely to need support in future, such as at the point when a child or young person moves into adult services. In some cases, where a person caring for an autistic child is not able to provide suitable accommodation or care and the wider family are unable to support, the local authority may provide specialist accommodation ([National Autistic Society](#)).

Social care professionals should be trained in autism awareness and managing autism and be able to provide individualised care. Any negative impact of the social and physical environment in which any part of the care process is provided should be minimised through reason adjustments (NICE CG170, 2013).<sup>16</sup>

##### *Autistic children in Social Care in Reading*

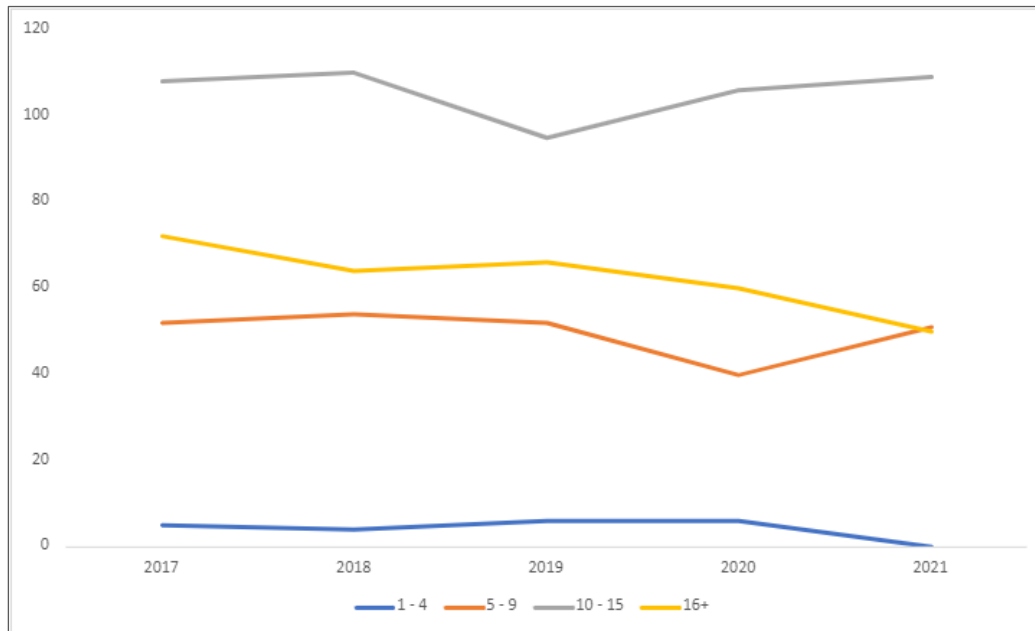
A total of 353 children with either an EHCP where ASD was identified as the primary need OR with a disability of autism were known to children’s social care or early help services in Reading between 2017 and 2021. Each year, around 150-200 were known to children’s social care and 30-60 to early help services.



**Figure 22. Number of autistic children known to children's social care and early help services in Reading each year 2017-2021** Source: Brighter Futures for Children

The total number of autistic children known to children’s social care and early help decreased slightly between 2017 and 2021. 23 fewer children were known to services in 2021 compared to 2017 - a decrease of 11%. The decrease was greater in children’s social care (46 fewer children, a decrease of 22%) while the number known to early help services increased by 19 children (59%).

This may reflect referral processes for the Children's Single Point of Access (CSPOA) for social care which do not currently capture whether a child is autistic. **Some local services have reported that they are supporting families with children with substantial needs who are not known to social care services, including children who attend special schools and are non-verbal or incontinent, significantly deprived and socially and economically marginalised.**



**Figure 23. Number of autistic children known to children's social care and early help services in Reading each year in each age group 2017-2021**

*Source: Brighter Futures for Children (a small number of children (less than 30) were known to both children’s social care and early help each year and have therefore been included twice in totals)*

Around half of the children known to services each year were aged 10-15 years, around a quarter were aged 5-9 years and another quarter 16 years and older. Only a small proportion were aged 1-4 and this is likely to reflect the smaller number who receive a referral or diagnosis at this young age.

The number of young people aged 16 and over who were known to services declined between 2017-2020, other age groups saw numbers fall in children’s social care services but increase in early help services.

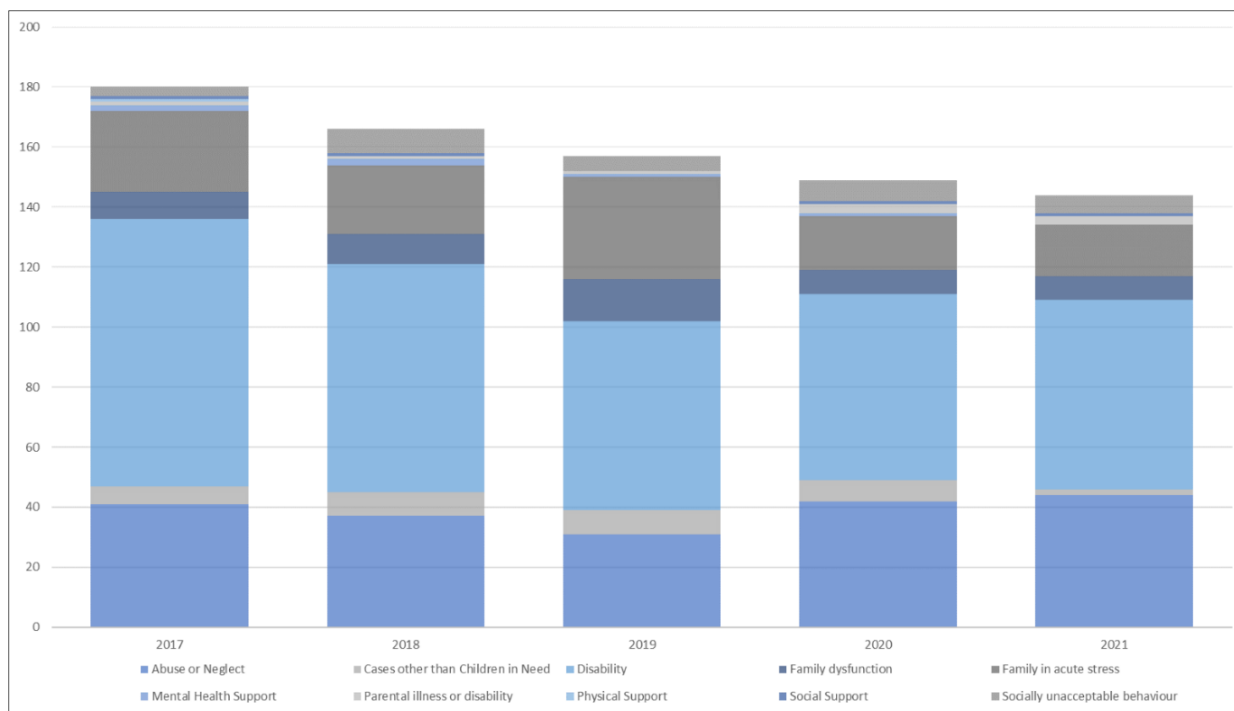


Figure 24. Number of autistic children known to children's social care by primary social care need 2017-2021

Source: Brighter Futures for Children

Most common social care primary needs for autistic children between 2017 and 2021 were disability (40%) or learning disability support (10%), abuse or neglect (22%) and families being in acute stress (14%). Although this picture seems to have remained constant over the period, the number of families assessed as being in acute stress seems to have temporarily increased in 2019 and 2020 and 2021 saw an increase in the number and % of children whose primary need was abuse or neglect.

### 6.1.2 Recommendations

- Ensure autistic children, including those who are marginalised or from seldom heard groups, who are eligible for children's social care are actively supported to access the help they need.** The number of autistic children known to children's social care in Reading has decreased in recent years. This does not correspond with the picture seen in schools or in population estimates, where the number of autistic children in Reading appears to be increasing. It will be important to ensure that this does not reflect additional barriers to accessing care. Some local experts have reported that autism may not be recorded for children with significant needs and that some marginalised families, often facing significant deprivation and language barriers, are not known to children's social care.
- Investigate increase in abuse/neglect as primary social care need.** The number of children known to services whose primary social care need was recorded as abuse or neglect increased in 2020 and 2021. This appears likely to be related to the Covid-19 pandemic and may represent a more general trend in primary social care needs of children known to children's services. School closures and the reduced opportunities to detect abuse during lockdowns were highlighted by the Children's Commissioner as likely to lead to an increase in referrals when schools re-opened. It will be important to identify the extent to which vulnerable autistic children have been disproportionately affected by lockdowns and school closures and whether there are any ongoing additional needs for this group as a result.

### 6.1.3 Mental Health

Nationally, autism prevalence within adult inpatient mental health settings is estimated to be 2.4-9.9%<sup>65</sup> while autistic people account for 1 in 100 people. Investigation and action to address the expected high prevalence of autistic adults in inpatient mental health settings and to tackle the over representation of autistic young people in mental health beds is needed.

Throughout the pandemic, inpatient mental health services have seen an increase in the number of autistic people. In Reading, mental health services are provided by:

- The Community Mental Health Team provided by BHFT
- Reading Borough Council Mental Health Social Care Team – for those with mental health issues and who have care and support needs.
- Mental Health Crisis Service - This team provides a 24/7 service
- Talking Therapies
- Compass Recovery College amongst other organisations.

Over the last few years the rate of referrals have increased which may be partly due to the effects of the pandemic. The exact number of people within the mental health service with an autism diagnosis and co-occurring conditions associated to mental health problems is unknown. Evidence reports a high proportion of autistic people will have a learning disability and most autistic children will likely have special educational needs (SEN).

#### *Data relating to Section 117 patients who have an autism diagnosis in Reading*

**Section 117 (s117)** – Some people who have been sectioned under the Mental Health Act 1983 (MHA 1983) will be entitled to free aftercare funding, known as s117 aftercare. s117 of the MHA 1983 sets out that these people who have been sectioned are entitled to aftercare to reduce the risk of their mental health deteriorating and therefore further hospital admissions.

The data below shows a breakdown of the small number of people from Reading who have autism / Asperger’s syndrome recorded as a diagnosis who are entitled to sec 117 aftercare. For just over half, autism or Asperger’s syndrome was not their primary diagnosis and many of those who did have autism or Asperger’s syndrome as a primary diagnosis also had at least one additional diagnosis, most commonly a learning disability, mental health need or both. Those who have sec 117 entitlement have a care package or are in a specialist hospital placement. Most people entitled to section 117 aftercare were in supported living accommodation (61%), which had an average cost of £2734 per week. Weekly cost in all provision types ranged from around £200 a week (direct payment) to over £5000 a week (supported living).

**Table 10. Section 117 patients who have an autism diagnosis, Reading (as at 4 March 2022)**

Provision	Autism/Asperger’s is primary diagnosis	Autism/Asperger’s is additional diagnosis	Total
Direct Payment	*	*	*
Residential	*	*	*
Supported Living	7	*	11
TOTAL	10	8	18

\*numbers under 5 suppressed to protect identities.

Some local commentators have described high numbers of autistic people admitted into inpatient mental health care, some of whom, they report, are receiving inappropriate care. This is a highly sensitive issue and more work to understand the local situation is needed.

<sup>65</sup> 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.



#### 6.1.4 Education

Many autistic children's lived experiences in education make it hard for them to learn and achieve to the best of their ability. Too many autistic children and young people report that their experiences leave them feeling unsafe, unhappy, excluded and lonely while their peers thrive.

Policy and systems created without autistic people in mind, matched with the sometimes-overwhelming sensory environment of the classroom, can cause significant over or under-stimulation and or anxiety. This emotional dysregulation (be that externalised or internalised) significantly impacts cognitive load and attention and can lead to relationship breakdowns. Learning for many autistic individuals is much harder than for their peers and for some becomes almost impossible.

As a result, autistic children are more likely to be excluded, feel like they are failing and underperform in tests and exams. They are also more likely to feel isolated, socially excluded and become mentally ill because of these experiences.

Many autistic children experience bullying, which has a significant impact on accessing education and mental health. Many autistic adults in Reading have shared that they have never recovered from their school experiences, with severe impacts on mental health, relationships and employment.

In [2017, the National Autistic Society](#) ran a parliamentary inquiry on education with the [All-Party Parliamentary Group on Autism](#):

- Fewer than half of children and young people say they are happy at school
- 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 say they are confident about supporting an autistic child
- Autistic children are twice as likely to be excluded from school. The most common reason being 'persistent disruptive behaviour'
- Autistic children are the most represented group at the Special Educational Needs and Disability Tribunal (SENDIST), which deals with certain appeals cases where a parent disagrees with an educational authority.

Settings that do not make reasonable adjustments for autistic children, or proactively take actions to improve their lived experiences, create inequality in opportunity and limit access to learning for those young people.

*Provision of information about support for children and young people with special education needs (SEN) – the Local Offer*

Special Educational Needs Local Offer regulations require local authorities to consult on and provide information about special educational provision provided through schools and other education providers for children and young people up to the age of 25 years who live in its area.

In Reading SEND (Special Educational Needs and Disabilities) and the local offer is delivered by Brighter Future for Children (BFfC), a not-for-profit company owned wholly by Reading Borough Council which operates independently of and in partnership with the Council.

[In 2021 a joint inspection of Reading by Ofsted and the Care Quality Commission](#) judged Reading's local offer to be amongst the strengths of the partnership. They identified that families had widespread awareness of the online resource and noted that the local offer team were effective in following up contacts to ensure that needs were met.

More information on Reading's Local Offer is available through the [Reading Services Guide](#)

## Schools

### Mainstream schools

Most autistic children attend a mainstream school and are able to progress and flourish. The APPGA highlights the importance ensuring that school staff at all levels have a good awareness of the needs of autistic children, including recognising that what might be perceived as ‘poor’ behaviour may reflect that some needs, such as feelings of anxiety, have not been met. They note the higher risk of exclusion amongst autistic children.

Adjustments to behaviour policies, providing ‘safe’ or quiet spaces, better understanding of sensory differences or other situations that may trigger ‘meltdowns’ can help to provide a supportive environment for autistic children and young people within mainstream schools.

The report also highlights autistic children’s experiences of bullying and isolation in school settings and suggests that greater awareness amongst staff may help to ensure that autistic children have greater support to dealing with bullying in schools.

### *Estimated number of autistic children in mainstream schools in Reading*

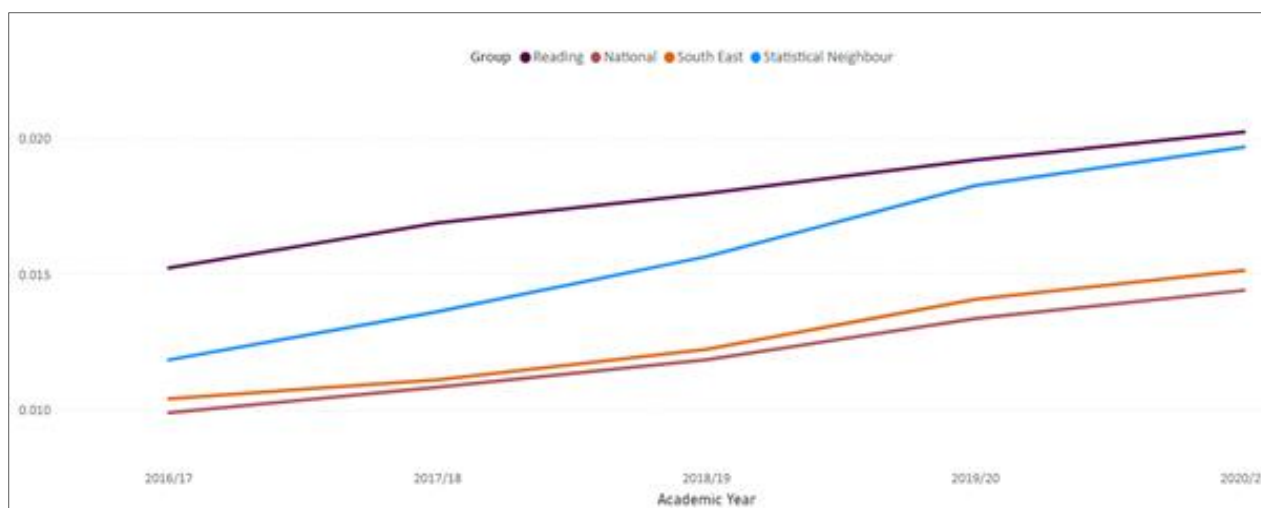
Estimated prevalence rates amongst school aged children in the UK (see Section 1: prevalence) suggests there may be around 10 autistic children who attend each non-selective secondary school in Reading and up to 18 children attending each of the largest secondary schools. Four autistic children are likely to attend each primary school, with 8 children attending each of the largest schools.

These are crude rates based on prevalence of autism amongst the whole school aged population in the UK and there may be differences between Reading and other areas. Information from BfC showing the percentage of children in Reading who have had autistic spectrum disorder (ASD) identified as their primary need in an education, health and care plan (EHCP) suggests that prevalence of autism may be higher than this estimate prevalence. An estimated 2% of children in mainstream primary and secondary schools in Reading have had ASD identified as a primary need, compared to a national rate of 1.44%. Using this estimate of prevalence would increase the average number of autistic children attending non-selective secondary schools in Reading to 19, with up to 30 attending the largest schools, and to 7 autistic children attending each primary school in Reading, including up to 14 children in the largest primary schools. It should also be noted that this proportion has increased over the last five years.

**Table 11. Percentage of children in mainstream primary and secondary schools in Reading with autistic spectrum disorder (ASD) identified as primary need on EHCP**

Academic Year		2016/17	2017/18	2018/19	2019/20	2020/21
Autistic Spectrum Disorder	Reading	1.52%	1.69%	1.80%	1.92%	2.02%
	National	0.99%	1.08%	1.18%	1.34%	1.44%
	South East	1.04%	1.11%	1.22%	1.41%	1.51%
	Statistical Neighbour	1.18%	1.36%	1.56%	1.82%	1.97%

Source: Brighter Futures for Children



**Figure 25. Percentage of children in mainstream primary and secondary schools in Reading with ASD identified as primary need on EHCP** Source: Brighter Futures for Children

Please note that these estimates refer to children who attend schools in Reading (which is different from children who are resident in Reading) and do not consider the numbers of autistic children who do not attend mainstream schools.

- Based on official prevalence estimates, EHCPs in Reading and the number of pupils attending Reading schools, most schools in Reading should anticipate that a small number of their pupils will be autistic and should plan to meet their needs accordingly; and
- Secondary schools should anticipate that between 10 and 30 of their pupils will be autistic.
- The number of autistic children in mainstream schools has increased steadily over the last five years and may be expected to continue to increase in the next few years.

#### *Autistic children and young people who need additional support*

Education, Health and Care Plans (EHCPs) are put in place for children and young people up to the age of 25. EHCPs identify educational, health and social needs and set out what additional support is required that cannot be provided through the standard level of provision of the school that the child or young person attends. Plans are developed based on EHC assessments carried out by the local authority, which can be requested by schools or parents for children and young people aged under 16 years, or by young people themselves when they are aged 16 years and older, and include details of education, health and social care needs and what additional provision will be put in place to meet those needs.

The SEND code of practice emphasises the need to make an assessment of needs across four broad areas:

- **Communication and interaction**, including difficulties with social interaction which may be related to autism and other speech and communication needs.
- **Cognition and learning**, including moderate, severe and profound and multiple learning difficulties and specific learning difficulties such as dyslexia and dyspraxia.
- **Social, emotional and health difficulties**, reflecting mental health difficulties or disorders.
- **Sensory and/or physical needs** such as a physical disability, vision, hearing or multi-sensory impairment.

When recording details of an EHCP local authorities are required to report the child's primary need as one of the following categories

- Speech language and communication needs
- Autistic spectrum disorder

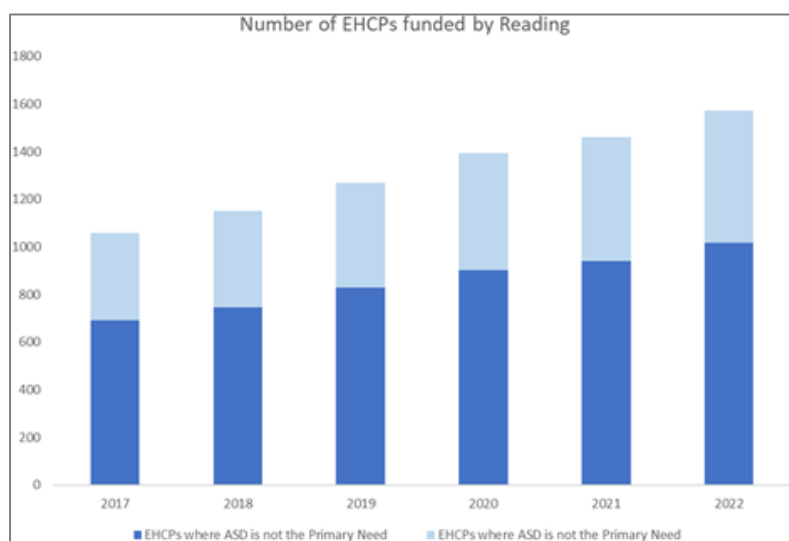
- Specific learning difficulties
- Moderate learning difficulty
- Severe learning difficulty
- Profound and multiple learning difficulty
- Social, emotional and mental health
- Visual impairment
- Multisensory impairment
- Physical disability
- Special educational need (SEN) support but no specialist assessment of need

Examining the number of EHCPs in Reading where ASD is the primary need can help understand trends in needs of autistic children and young people in schools, Further & Higher education in Reading. It must be noted, however, that most children's needs are not fully encompassed by a single category of need and there may be a range of co-occurring or competing needs to be considered.

### *Prevalence and trend*

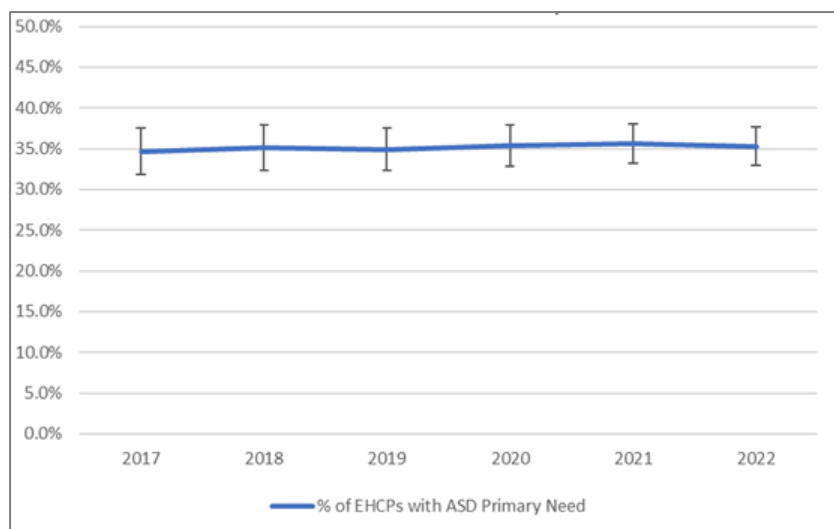
Since 2017 the total number of EHCPs funded by Reading has increased by an average of 8% each year, from 1,059 in 2017 to 1,572 in 2022.

The number of Reading EHCPs where ASD is recorded as the primary need have increased by a similar proportion and have consistently represented around 35% of all EHCPs each year. This is a slightly higher proportion than nationally, with APPGA reporting that ASD was the primary need for 27% of children with EHCPs in England in 2017.



**Figure 26. EHCPs funded by Reading Borough Council and number where ASD was identified as primary need (2017-2022)**

Source: Brighter Futures for Children



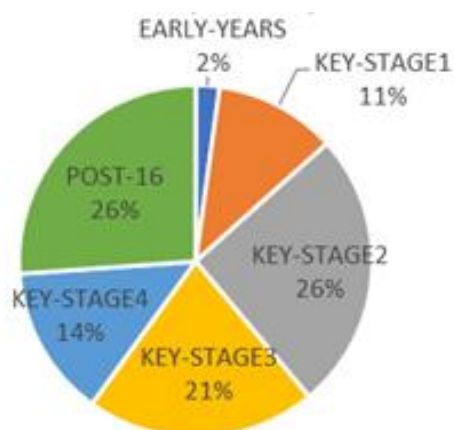
**Figure 27. Percentage of EHCPs in Reading where ASD was identified as primary need (2017-2022)**

Source: Brighter Futures for Children

Almost all children funded by Reading with an EHCP where ASD was the primary need lived within Reading Borough and more than two thirds attended a school in Reading. A total of 2,725 EHCPs were funded between 2017 and 2022, equivalent to an estimated 715 children and young people per 100,000 of the 0-25 year-old population had an EHCP with ASD as primary need between 2017 and 2020.

#### Key stage

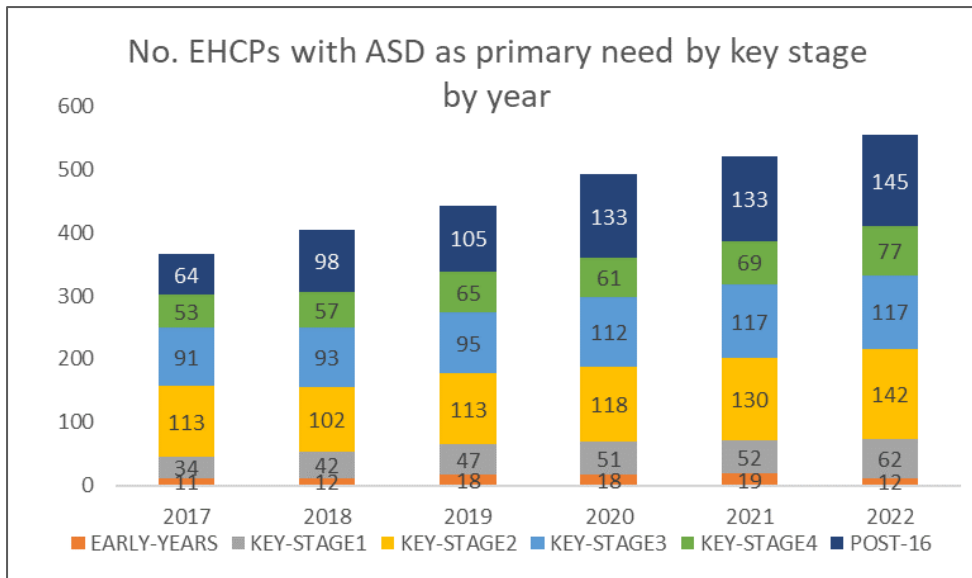
Except for early years, where children may be too young to be diagnosed as autistic, children and young people in Reading with EHCPs with ASD as primary need in 2022 were represented in every key stage. Around a quarter were in post-16 education, around a quarter were in Key Stage 2 (school years 3-6, ages 7-10 years) and around a fifth were in Key Stage 1 (school years Reception – 2, ages 4-6 years).



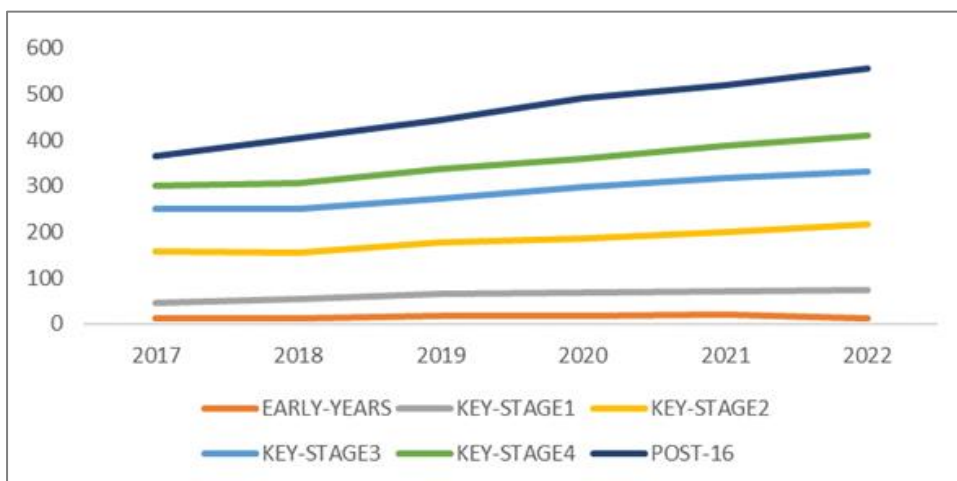
**Figure 28. Children and young people with EHCPs with a primary need of ASD by key stage (2022)**

Source: Brighter Futures for Children

The number of EHCPs with ASD as a primary need has also increased over time in each key stage. The largest increases between 2017 and 2022 were amongst young people aged 16 or over and children in key stage 1, but this should be seen in a context of increasing numbers in all age groups.

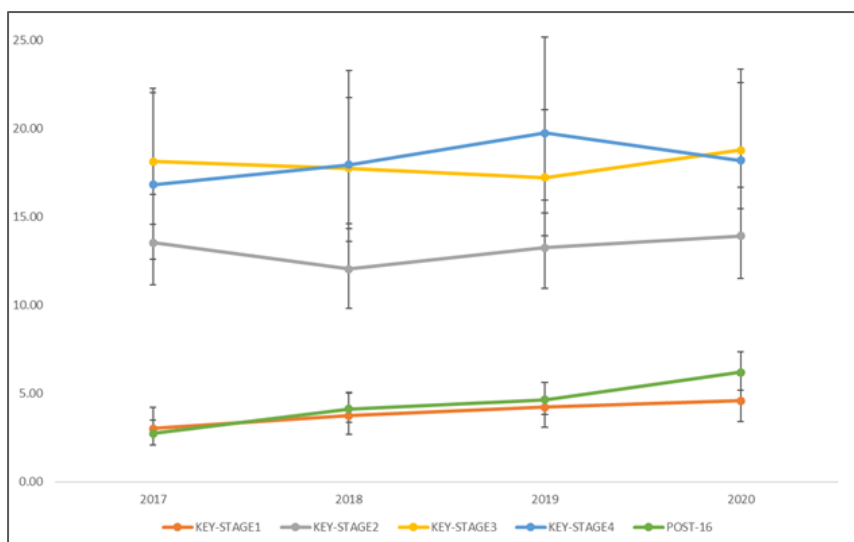


**Figure 29. Children and young people with EHCPs with a primary need of ASD by key stage (2017-2022)**  
 Source: Brighter Futures for Children



**Figure 30. Children and young people with EHCPs with a primary need of ASD by key stage, Reading (2017-2022)**  
 Source: Brighter Futures for Children

Although much of this increasing trend can be attributed to increases in the number of people in these age groups in the population, the rate of EHCPs where ASD is a primary need in the under 25 population also shows some increases between 2017 and 2022. Overall, for all age groups from KS1 to Post-16, prevalence per 1,000 increased from 7 per 1,000 in 2017 (95% CI 6.2-7.7) to 9 per 1,000 in 2020 (95% CI 8.6-10.3). On the whole increases within key stage groups were not large enough to be statistically significant, but there has been a significant increase in the rate of young people with ASD as a primary need in the post-16 stage of education between 2017 and 2020, with the rate increasing from 2.74 per 1,000 in 2017 (95% CI 2.11-3.5) to 6.22 per 1,000 in 2020 (95% CI 5.2-7.36). The increase in key stage 1 from 3 per 1,000 in 2017 (CI 95% 2.0-4.3) to 4.5 per 1,000 (CI 95% 3.4-6.0) is also close to significance.

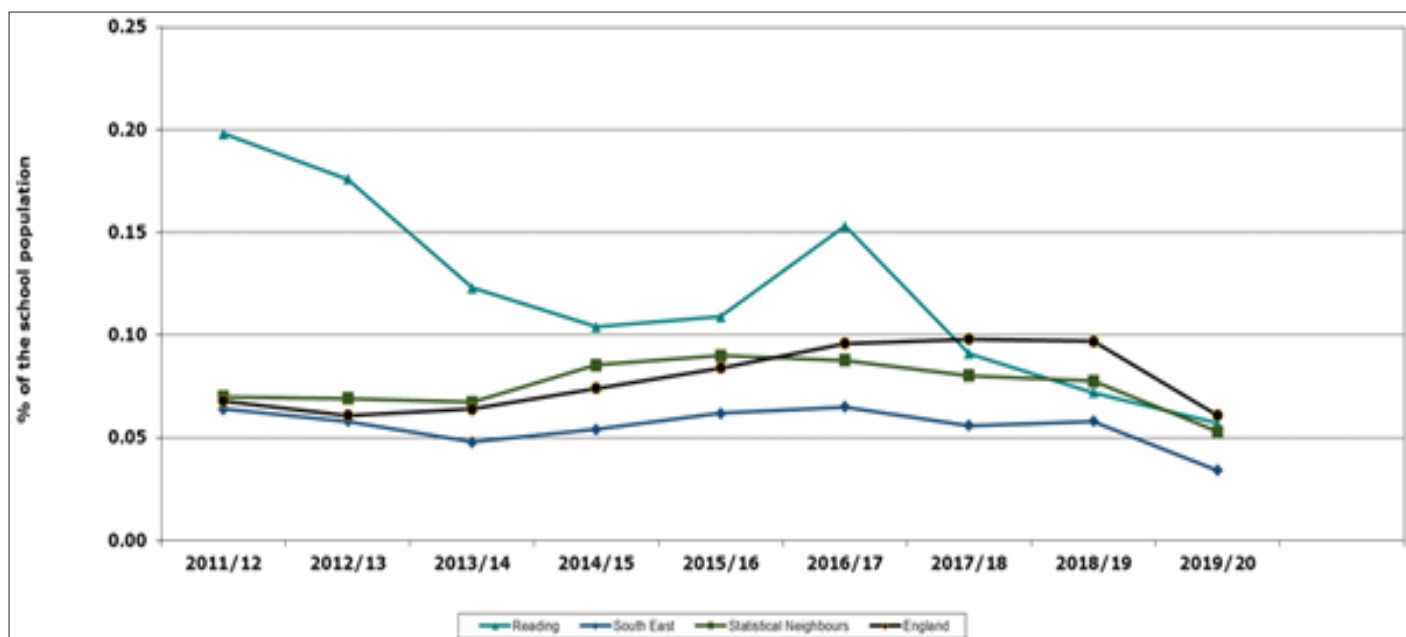


**Figure 31. Rate of children and young people with EHCPs with a primary need of ASD by key stage, Reading (2022)**  
 Source: Brighter Futures for Children/ONS mid-year population estimates 2020

### Exclusions

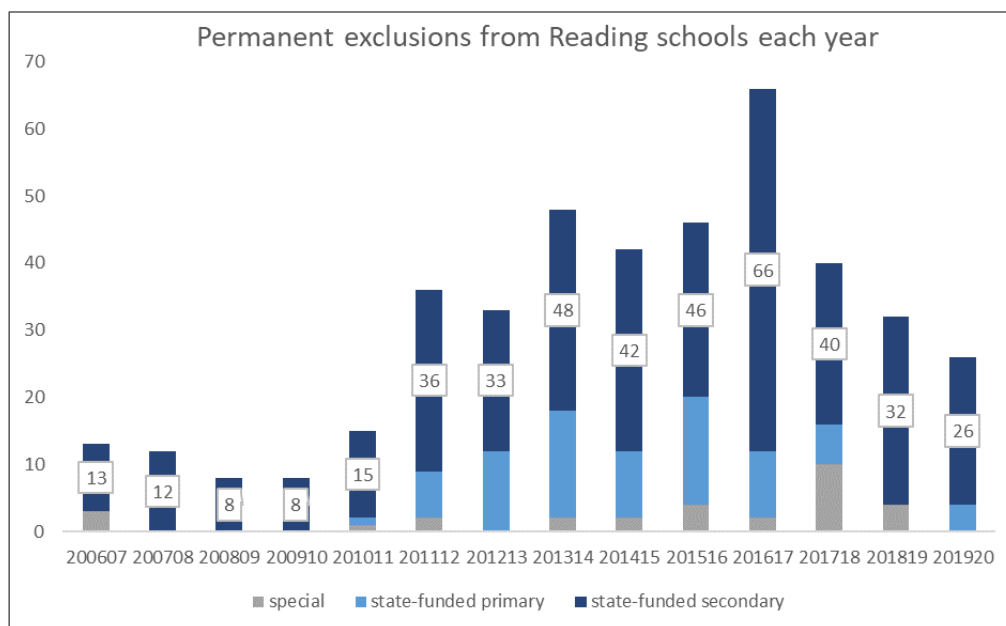
The rate of exclusion of autistic children can be an indicator of whether appropriate adjustments have been made to school environments. As both the total number of children who are excluded in Reading and the number of autistic children are relatively small, however, and as the number of exclusions of autistic children in Reading is not available as a separate figure, it is not clear whether it will be practical or possible to draw conclusions from such a comparison.

The Department for Education’s Local Authority Interactive Tool (LAIT) reports that the total percentage of all children in Reading who received a permanent exclusion fell from 0.153% in 2016/17 to 0.06% in 2019/20 and is now in line with averages of both England and Reading’s statistical neighbours (although still higher than the South-east average). Based on the most recent school-aged population, this is equivalent to around 15 exclusions in a school year.



**Figure 32. Total permanent exclusions from school as a percentage of the school population**

Information collected separately via the school census and published via Explore Education Statistics suggests a reducing number of exclusions each year, including 26 in 2019/20 comprising 22 in secondaries, 4 in primaries and none in special schools.



**Figure 33. Permanent exclusions from school, special school, state-funded primary, state-funded secondary, Reading, 2006/07-2019/20.** Source: Permanent and Fixed Period Exclusions in England: 2019/20 Academic Year [Permanent exclusions and suspensions in England, Academic Year 2019/20 – Explore education statistics – GOV.UK \(explore-education-statistics.service.gov.uk\)](https://www.gov.uk/explore-education-statistics.service.gov.uk). Information collected via the school census.

Locally produced BfC education performance indicators for the period between September 2021 and January 2022 show 13 permanent exclusions including 4 exclusions of children and young people with a SEN EHCP. Both total and SEN exclusion figures show a small increase since the previous school year, although this picture may be affected by school closures during 2020/21.

It may be possible to provide the number of exclusions of autistic children and young people in Reading and this should be explored. However, while this information, collected over a number of years, may be used to compare to rates of exclusion in all children or in autistic children in other areas, it seems likely that contextual information describing the circumstances surrounding any exclusions may prove to be equally useful in understanding whether needs of autistic children and young people are being met in local schools.

### *Autism Awareness in Schools*

Until 2022 individual schools in Reading were responsible for commissioning and completing autism awareness training for staff. To ensure consistency across all schools in Reading, BfC have recently established a Reading Autism Education Trust (AET) training hub accessible by all schools. Training is designed to raise awareness about autism amongst school staff and schools will be asked to embed AET standards and competencies. Training will be offered for all educational settings in Reading to purchase from February 2022. Training will be made available to BfC staff and other public and voluntary organisations from 2022 and education and childcare settings will also be offered the opportunity to buy Attention Autism training and Intensive Interaction training in late 2022.

The AET is an acclaimed not-for-profit programme led by two national autism charities – the National Autistic Society and Ambitious about Autism. Supported by the Department for Education, the AET promotes and supports partnerships throughout the education system to improve educational access, experience, and outcomes for autistic children and young people



BFfC was accepted as a Local hub provider in 2020 and now has a social franchising agreement in place. The work of the BFfC Reading Hub will centre on the promotion of good practice standards for education settings. The hub will provide a range of professional development training programmes for early years, settings, and post 16 settings delivered by local licensed trainers. Applications for AET trainers have been accepted from resource leads, special settings, mainstream settings and advisory services to position existing experts as local systems leaders.

Although evaluating levels of autism awareness in staff is challenging, monitoring take-up of the training and gathering feedback from staff, children and young people and families and carers may be useful to understand the effectiveness of the initiative.

### *Special schools*

Children and young people with an EHCP or their parents or carers have a legal right to request their preferred school or college. If they prefer to be educated in a mainstream school, they must be given this opportunity unless all possible steps have been taken to accommodate them and the school has been shown to be inappropriate for their needs or accommodating them is incompatible with the needs of other pupils.

They may also request a place at a special school, defined by the Education Act as a school that is “specially organised to make special educational provision for pupils with SEN” or a specially resourced unit based within a mainstream school.

Brighter Futures for Children reports that there are currently 402 places at schools in Reading with special provision. These include 301 places in dedicated special schools, as follows.

#### *Special school places*

- 205 places at the [Avenue School](#), a day special school for boys and girls from the age of 2-19 with a severe learning difficulty and who may also be autistic, have a profound and multiple learning difficulty, speech and language needs, physical needs or a combination of any of these needs.
- 32 places at the [Holy Brook school](#), a special school for pupils with a severe social, emotional and mental health difficulty and who may have additional needs including learning difficulties or autism.
- 64 places at [Hamilton school](#), a social, emotional and mental health special school for those with an EHCP.

The remaining 101 places are in special resource centres based within mainstream primary and secondary schools.

#### *Special resource centre places in mainstream primary schools*

- 21 places in a specialist resource centre at Christ the King primary school
- 12 places in a specialist resource centre in EP Collier primary school
- 8 places in a specialist resource centre in Southcote primary (increasing to 12 in September 2023)

#### *Special resource centre places in mainstream secondary schools*

- 30 places in a specialist resource centre in King’s Academy Prospect secondary school & sixth form
- 25 places in a specialist resource centre in Blessed Hugh Farringdon secondary school
- 5 places in a specialist resource centre in Highdown secondary school

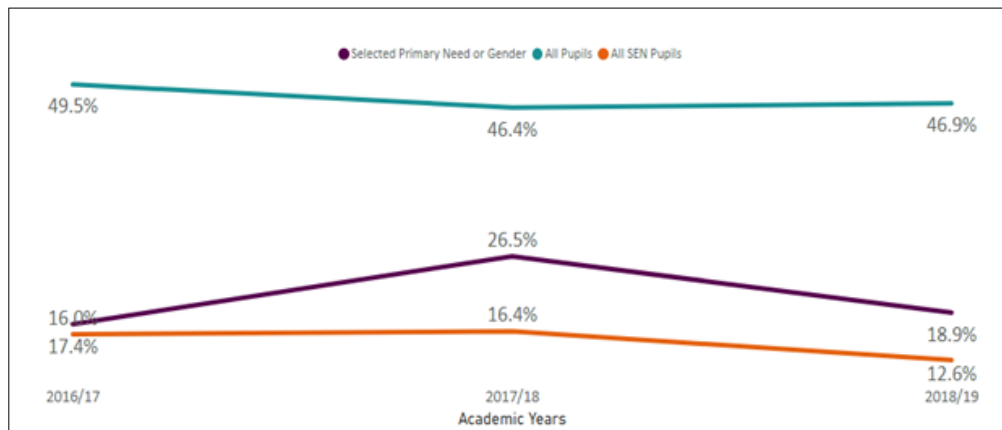
In 2019 BFfC’s SEND needs assessment reported on capacity in special schools and forecast anticipated number of required places. Although a relatively high proportion of pupils with an EHCP maintained by Reading attended a special school outside of Reading, the majority of these attended a school very close to Reading’s border with West Berkshire.

Feedback for this needs assessment has also highlighted limited specialist provision and staffing capacity for children with complex needs that may include autism or neurodiversity.

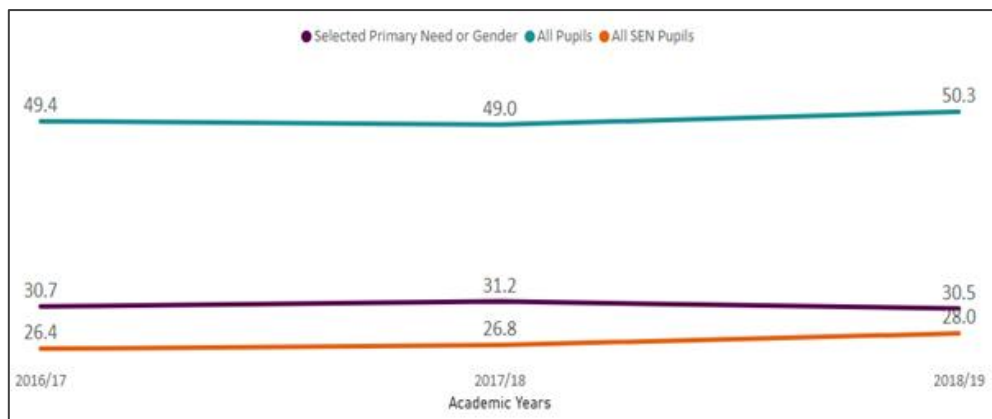
### Attainment

All pupils should have access to a broad and balanced curriculum and teachers should set high expectations and set ambitious targets. Analysis of attainment by pupils with ASD identified as primary need on an EHCP indicates attainment below that of all pupils, but higher than those with other SEN needs.

#### Key stage 4 – Attainment 8



**Figure 34. Percentage of pupils achieving 5+ in English and Mathematics GCSEs in Reading schools – Pupils with ASD identified as primary need in EHCP compared with all pupils and all SEN pupils (including those receiving SEN support)**  
Source: Brighter Futures for Children KS4 (Key Stage 4) Attainment Summary



**Figure 35. Average Attainment 8 score across Reading schools – Pupils with ASD identified as primary need in EHCP compared with all pupils and all SEN pupils (including those receiving SEN support)**  
Source: Brighter Future for Children KS4 Attainment Summary

Comparison of attainment of pupils with EHCPs at the end of Key Stage 4 in other local authority areas suggest that attainment in Reading is in line with other areas, with attainment slightly higher than England and statistical neighbours in the last three years. It is not possible to compare attainment of those with specific primary care needs.

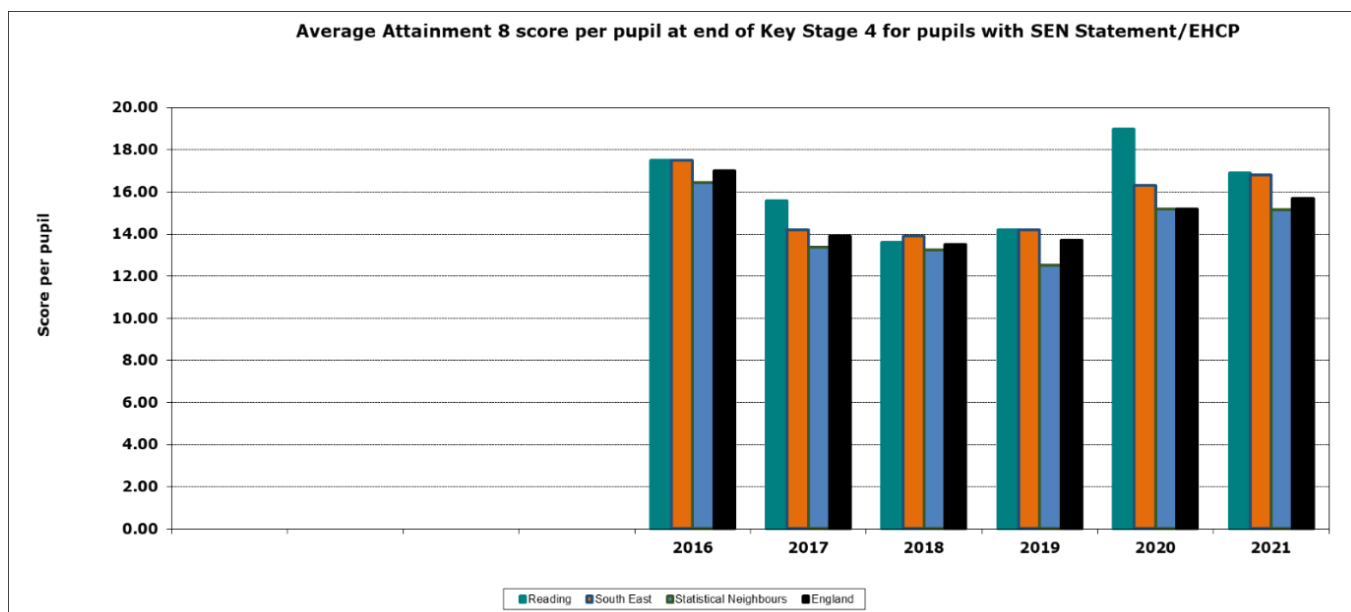


Figure 36. Average Attainment 8 score for pupils with SEN statement or EHCP – Reading compared with South-East, statistical neighbours and England Source: Local Authority Interactive Tool (LAIT) December 2021

Key stage 2 – Reading, Writing and Maths

A similar comparison for KS2 attainment suggests that more children with EHCPs in key stage two achieve an expected level in reading, writing and maths than in other areas. Attainment was especially high in 2019, but care should be taken in interpreting these figures where the number of children is likely to be relatively small and there appears to be a large discrepancy which may have arisen by chance.

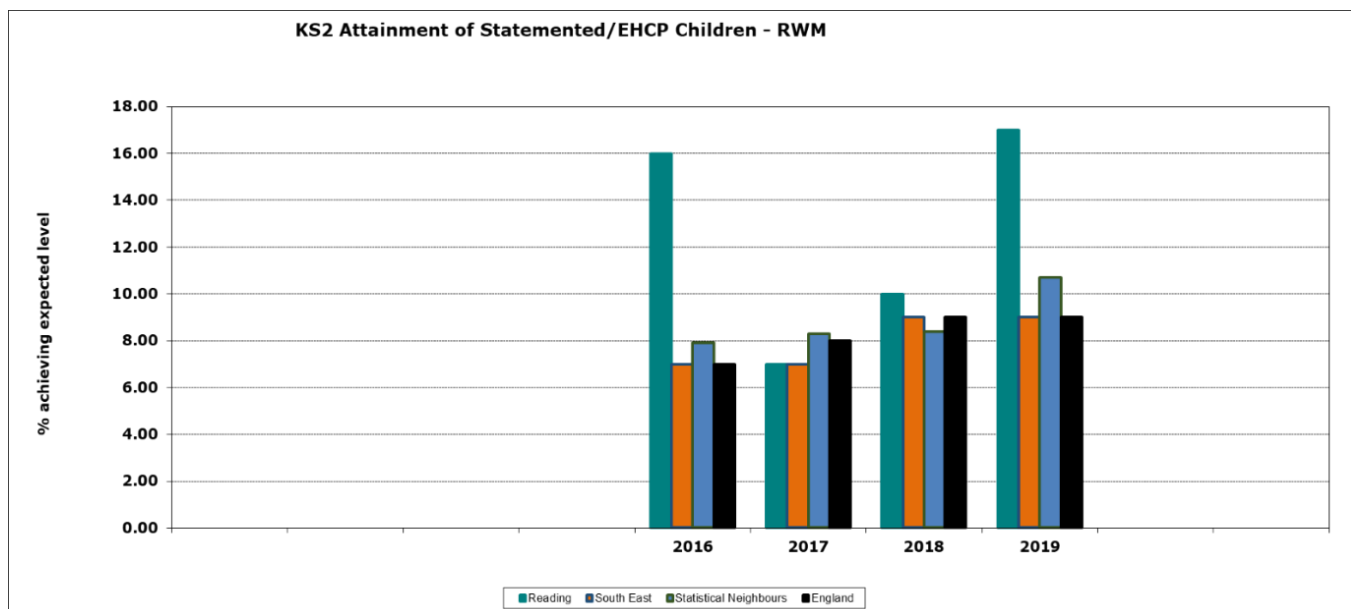


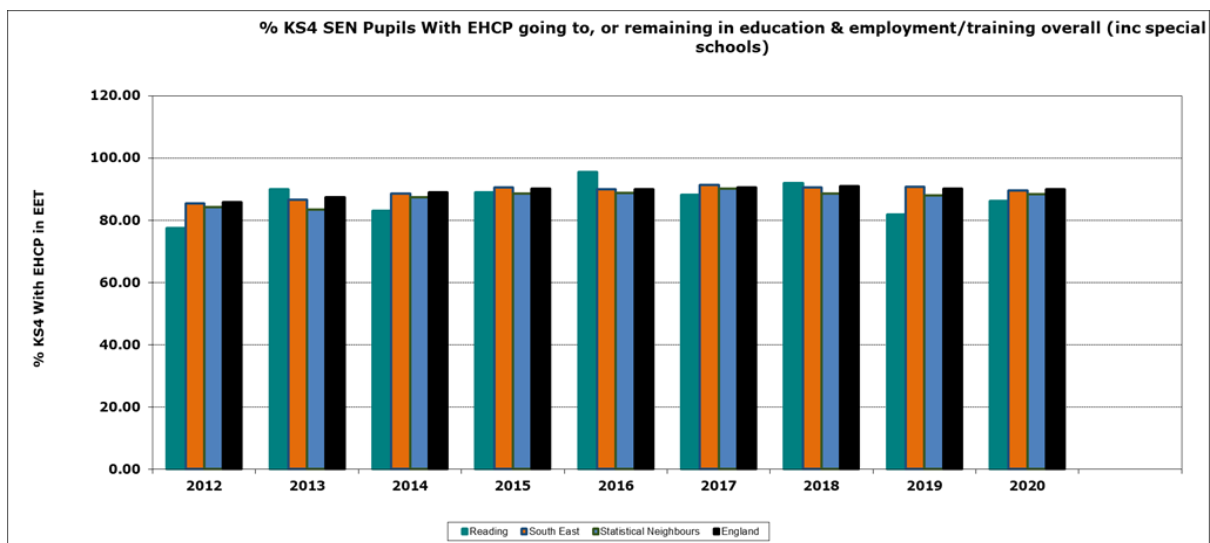
Figure 37. KS2 Attainment of Statement/EHCP Children – RWM Source: Local Authority Interactive Tool (LAIT) December 2021

*Preparing for adulthood in mainstream schools*

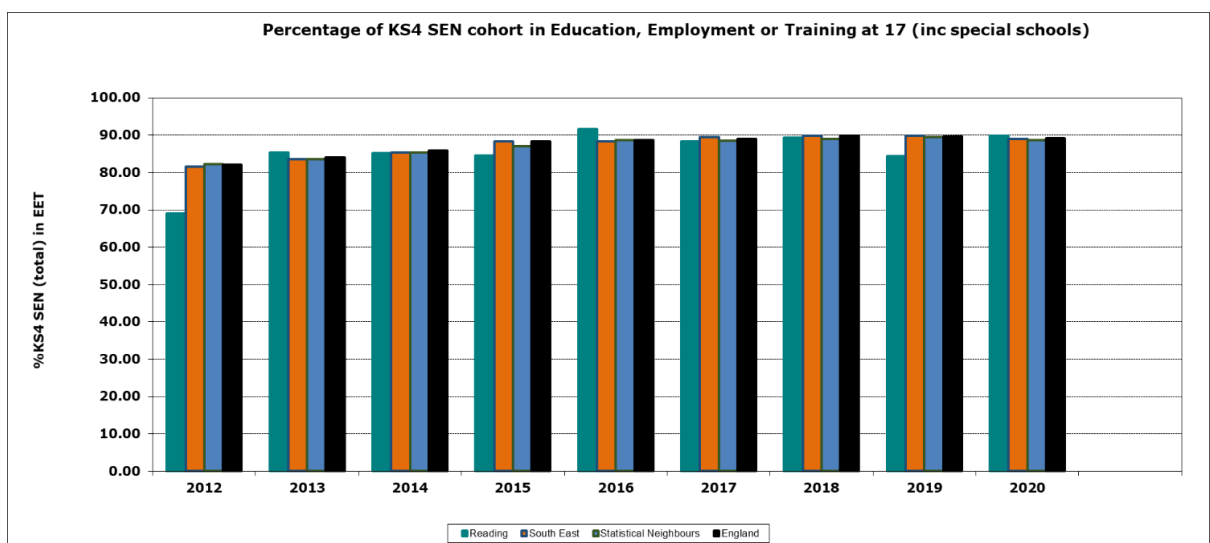
[The SEND code of practice](#) places an obligation on local authorities to begin planning for adulthood for children with SEN from the earliest years. This could mean working towards entering higher education or employment, preparing for independent living, making social connections and being part of a local community and living a healthy adult life.

Analysis within the Department for Education’s Local Authority Interactive Tool (LAIT) suggests the proportion of young people with an EHCP who go on to employment, education or training at the end of KS4 and who remain in employment, education or training by age 17 appear to be in line with other areas and the England average, but the proportion educated to levels 2 and 3 at age 19 was much lower than average. The need for better support for 16 and 17 year olds with SEND into work was highlighted by Ofsted and the Care Quality Commission (CQC) in their recent assessment.

[Preparing for Adulthood](#) (PfA) minimum standards, funded by the Department for Education, set out criteria for assessing whether appropriate support is provided, including legal duties for local areas.



**Figure 38. Percentage of key stage 4 pupils with an EHCP who go on to education, employment and training (including those who attend special schools)** Source: Local Authority Interactive Tool (LAIT) December 2021



**Figure 39. Percentage of key stage 4 pupils with an EHCP who are still in education, employment and training at 17 years (including those who attend special schools)** Source: Local Authority Interactive Tool (LAIT) December 2021

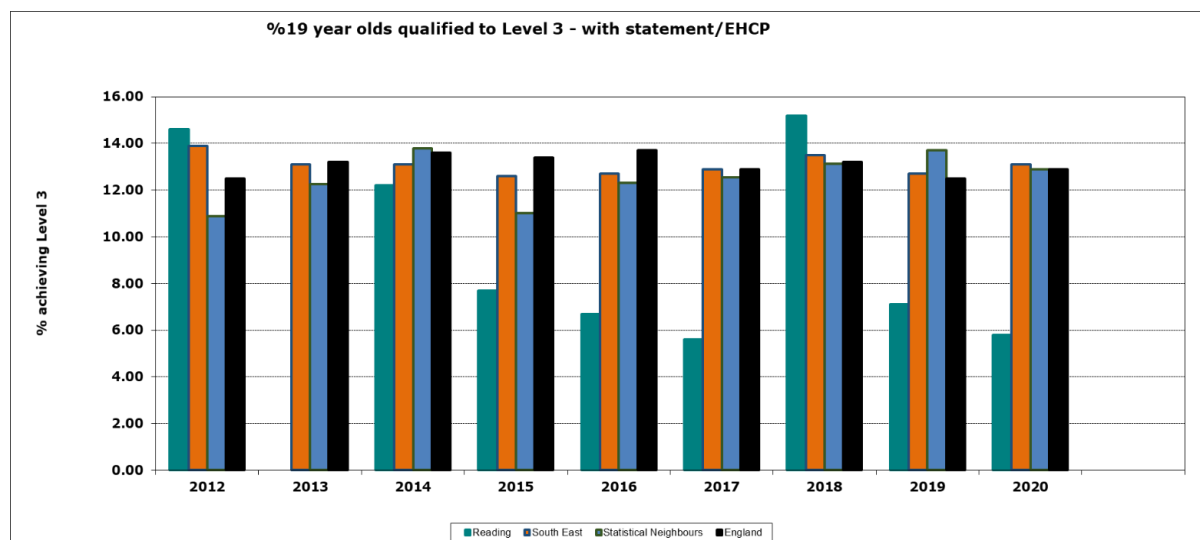


Figure 40. Percentage of 19 year olds with EHCPs qualified to level 3  
Source: Local Authority Interactive Tool (LAIT) December 2021

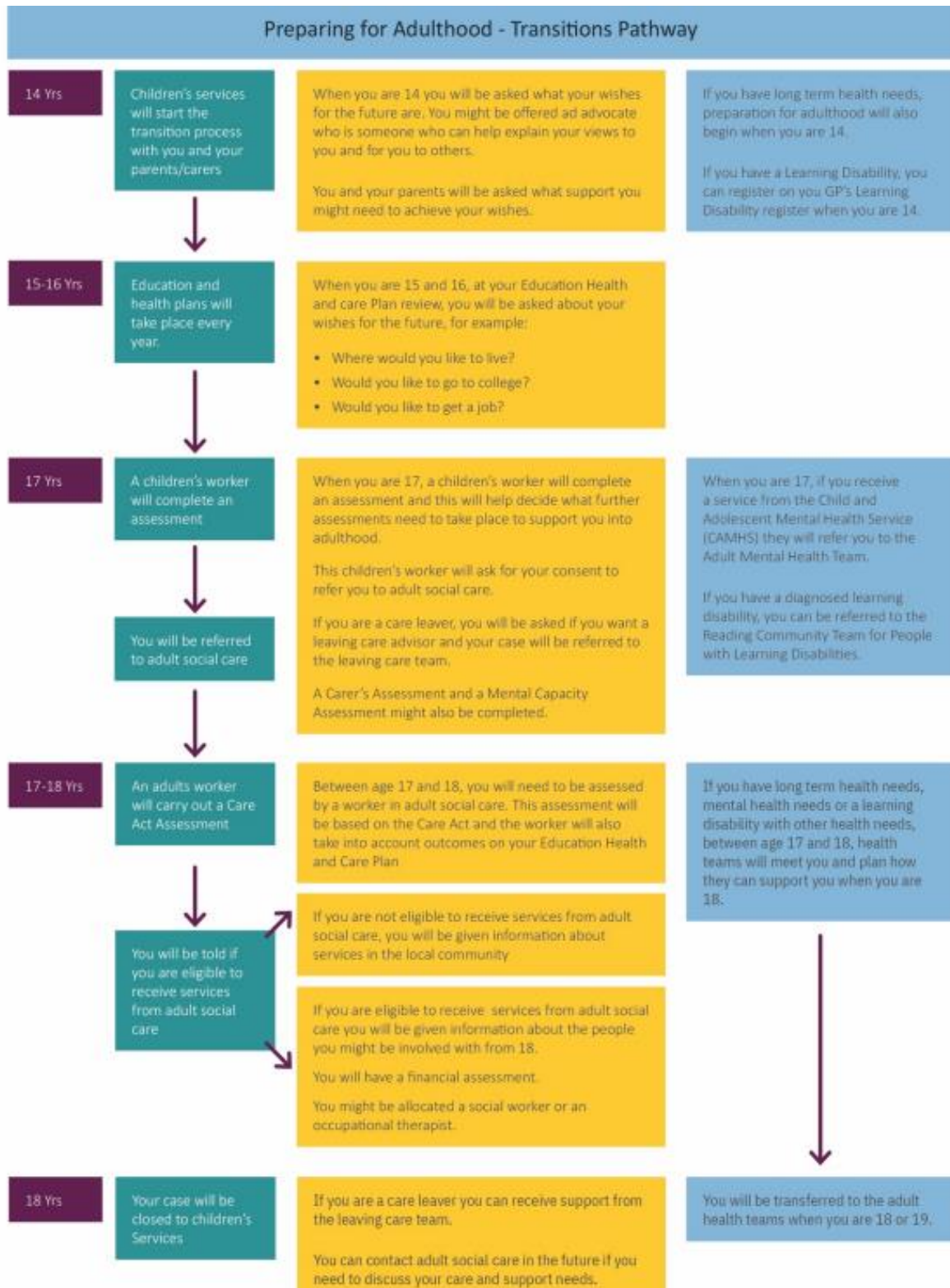
### 6.1.5 Recommendations

- Monitor and evaluate AET training in mainstream schools** - most autistic children are educated in mainstream schools and raising awareness of the needs of autistic children is likely to promote good outcomes. Information about prevalence of autistic children and young people suggests that most schools in Reading should expect that a small number of their pupils will be autistic. Larger secondary schools should expect up to 30 autistic children and young people to attend their school. As well as uptake of the training by schools, the views of autistic children and their families and carers on their school environment and should be sought.
- Culture change in schools** – in addition to awareness raising in schools, a range of measures will be required, including zero tolerance policies for bullying, autistic champions in schools, and regular whole school and class discussions.
- Review exclusions of autistic children** – as number of exclusions of autistic children are likely to be very small and comparison of rates therefore may not be useful, scrutiny of the circumstances in which autistic children are excluded may help to reassure local stakeholders that school environments are appropriate for autistic children.
- Capacity in specialist settings** - feedback for this needs assessment has highlighted limited specialist provision and staffing capacity for children with complex needs that may include autism or neurodiversity. A long-term strategy to address this is recommended.
- Preparing for adulthood** – Qualifications amongst young people with SEND appear lower than average in Reading and support for young people with SEND to access employment and education was also highlighted by Ofsted and CQC as an area for development. Analysis of EHCPs where ASD is primary need suggest an increasing trend in the number of autistic young people aged 16 and older, which may indicate that demand for support into education, employment and training for autistic people may also increase. New minimum standards for preparing for adulthood funded by the Department for Education have recently been published and may provide a useful framework to build on the initiatives outlined in the recent Ofsted and CQC assessment.

## 6.1.6 Transition into adult services

### Local Picture

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 shown below:



The Preparing for Adulthood Panel has responsibility for co-ordinating the 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 aged 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*

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

### *Healthcare transitions*

Within Berkshire Healthcare Children, Young People and Family Services, for those 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 services<sup>66</sup>:

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

### *Best Practice*

[NICE guidance](#) on transition from children's to adults' services (1.8) 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<sup>18</sup>.

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<sup>66</sup> 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>.

## 6.2 Adults

### 6.2.1 Adult Social Care

This section utilises information on autistic people residing in Reading held within the Mosaic Electronic Social Care System, which is Reading Borough Council's Adult Social Care dataset. With very small numbers recorded, data has been grouped into age bands of 18-64 and 65-84, split by gender and service user of referral, assessment or review. A current snapshot of the data gives counts of autistic people using a service.

#### *Data definitions:*

**Number of current open service users with Autism / Asperger's** – Currently active on the Adult Social Care system receiving a tangible current service (including professional support / support via a support worker) or in process of receiving a service via an ongoing assessment process with a recorded diagnosis on the electronic care system.

**Service User Referral** – Contact/Referral completed via the Adults Social Care Teams for new people not known to Adult Social Care on the system at that point in time. No current open work was ongoing until that point.

**Service User Assessment** – As a result of a referral an assessment process to identify the needs of the service user has been completed by Adult Social Care Teams. This includes those receiving a normal Assessment via what is referred to as an Assessment Planning Tool document, those receiving a specialist Mental Health Act assessment and those receiving a specialist Sensory Needs Assessment.

**Service User Review** – After an assessment process and subsequent services are provided a review is an examination of an existing client's needs and services (the care plan where it exists) which must include a (formal) reassessment, irrespective of whether it was a scheduled or unscheduled review. A scheduled review may be undertaken at regular intervals or by a predetermined date. A review must have been carried out or commissioned by the CASSR.

#### *Data caveats:*

1. The following data is sourced from Adult Social Care and therefore relates to autistic people who are known to and recorded with the Mosaic Adult Social Care system.
2. The Mosaic Adult Social Care system does not require the mandatory recording of autism for autistic people within the system. As a result, the quality of the data held is more difficult to quantify.
3. The system does not state the primary reason for an individual being in contact with Adult Social Care and therefore we cannot make assumptions as to why a person is using a service (i.e., whether they are in contact due to their autism or for another reason).
4. Data counts of less than 5 cannot be used for data analysis, therefore \* or no data might represent a count of < 5 and must be read with caution or be summed into a broader grouping.
5. Data has been split into two sections – autism excluding Asperger's Syndrome/high functioning autism and Asperger's Syndrome/high functioning autism as recorded on the reporting system.
6. The data window of April 2019 to December 2021 covers just under a 3 year period, during which there has been a COVID-19 pandemic (March 2020 to present).

*Current snapshot (as of 12<sup>th</sup> January 2022) (Source: RBC Adults Social Care)*

Of the 160 autistic people currently known to Adult Social Care in Reading Borough Council, 76% have autism (excluding Asperger's Syndrome/high function autism) and 24% have Asperger's Syndrome/high functioning autism. 75% are male and 24% are female.



Table 12. Estimated no. of people known to ASC (Autism [excl. Asperger’s Syndrome] & Autism, Reading

	By Gender			Total	Percentage By gender			Total
	Male	Female	Indeterminate		Male	Female	Indeterminate	
Number of current open service users in RBC with Autism (excluding Asperger’s Syndrome / High Functioning Autism)	89	32	*	121	74%	26%	-	76%
Number of current open service users in RBC with Asperger’s Syndrome / High Functioning Autism	31	7	*	38	82%	18%	-	24%
Total	120	39	*	159	75%	25%	-	100%

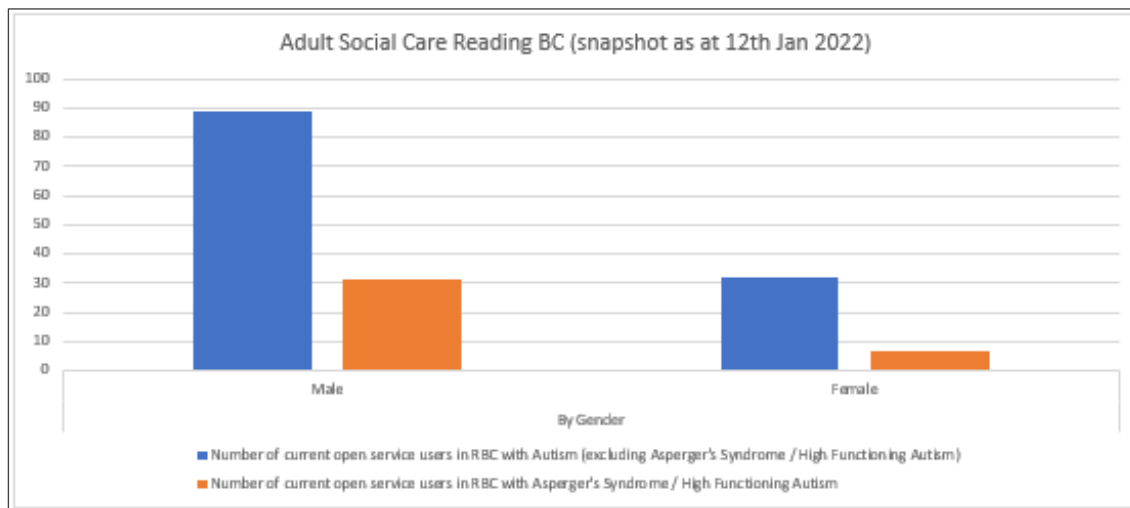


Figure 41. Number of current open service users in RBC with Autism (excl. Asperger’s Syndrome) and numbers with Asperger’s Syndrome by Gender, Reading, Jan 2022

Current snapshot of users by service type, shows a proportionally higher uptake for those with Asperger’s Syndrome/high functioning autism within Supported Living, Extra Care at Home and No Ongoing Services. NB: primary reason for using Adult Social Care services is not known therefore might not relate to autism.

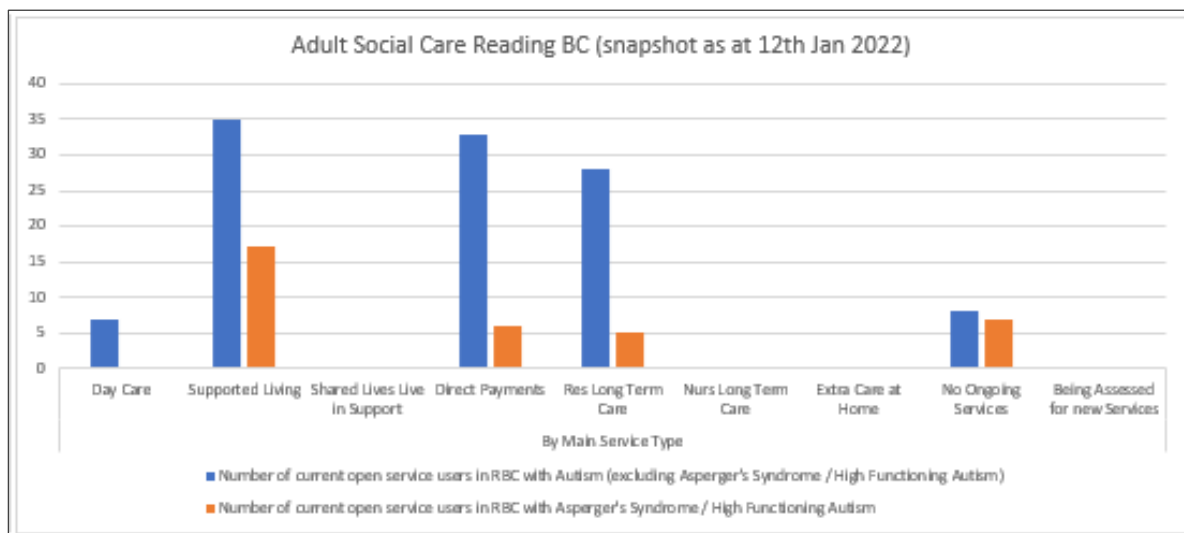
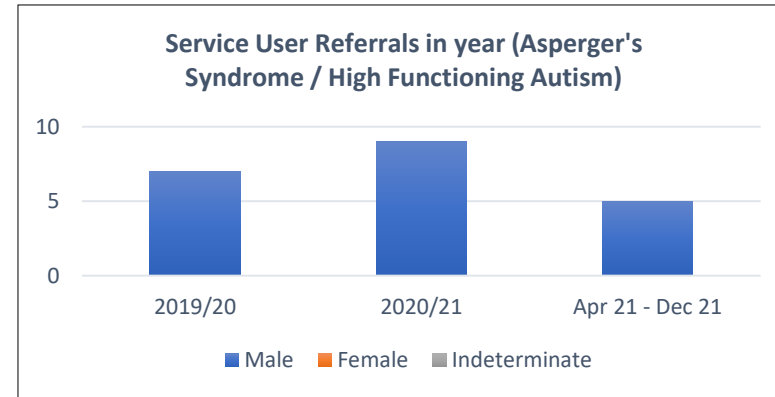
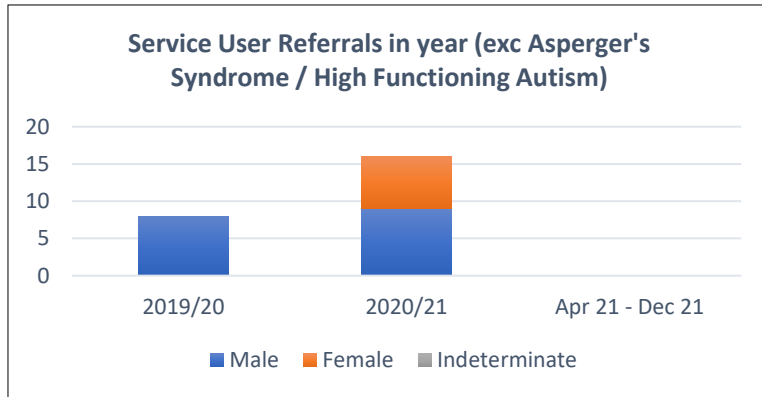


Figure 42. Number of current open service users in RBC with Autism (excl. Asperger’s Syndrome) and numbers with Asperger’s Syndrome by Main service type, Reading, Jan 2022

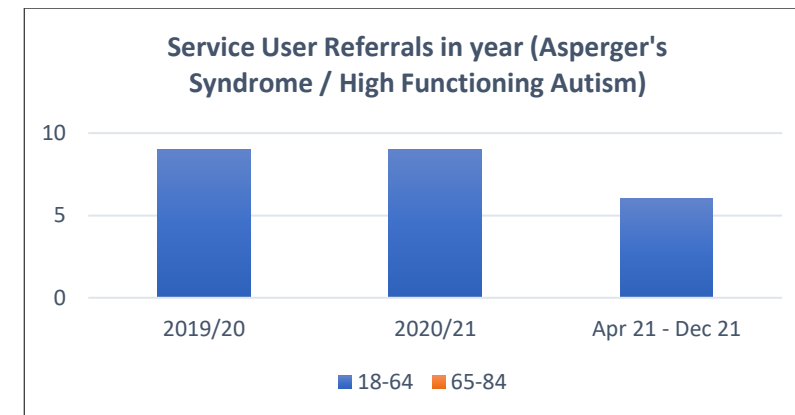
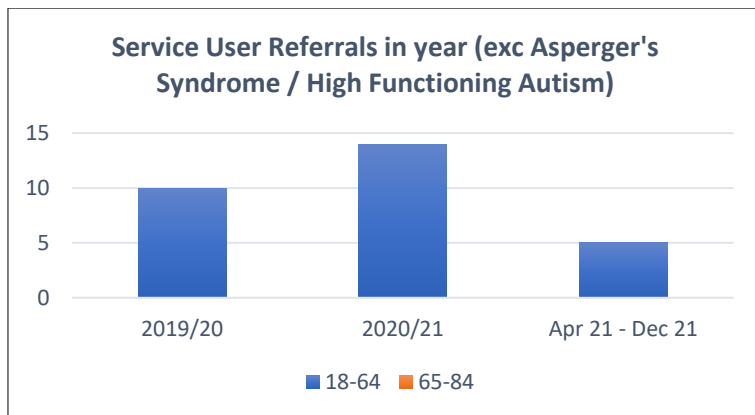
*Service users – referrals*

Within autistic people (excluding Asperger’s/high functioning autism), the gender split shows marginally more males than females being referred. (18 males compared with 14 females across the period). This differs from the overall gender split of autistic people of 3 to 1 male to female currently using Adult Social Care services. (Counts of < 5 suppressed from the charts.)



*Figure 43. Service users referrals in year Autism (excl. Asperger's Syndrome) and referrals with Asperger's Syndrome by Gender, Reading, 2019/20-Dec 2021*

By age band, numbers are <5 for referrals relating to 95-84 for autistic people, but zero for 65-84 year olds with Asperger’s Syndrome/high functioning autism. (See data caveats with reference to the small amount of data for Asperger’s Syndrome/high functioning autism)



*Figure 44. Service users referrals in year Autism (excl. Asperger's Syndrome) and referrals with Asperger's Syndrome by Age, Reading, 2019/20-Dec 2021*

*Service users – assessments*

Service user assessments have decreased for autistic people with Asperger's Syndrome/high functioning autism across the 3 year period, whereas there was a large increase during 2020/21 of assessments for autistic people (excluding Asperger's Syndrome/high functioning autism). The gender split for service user assessments shows greater difference across the 3 year bands for those with autism (excluding Asperger's Syndrome/high functioning autism), than for those with Asperger's Syndrome/ high function autism

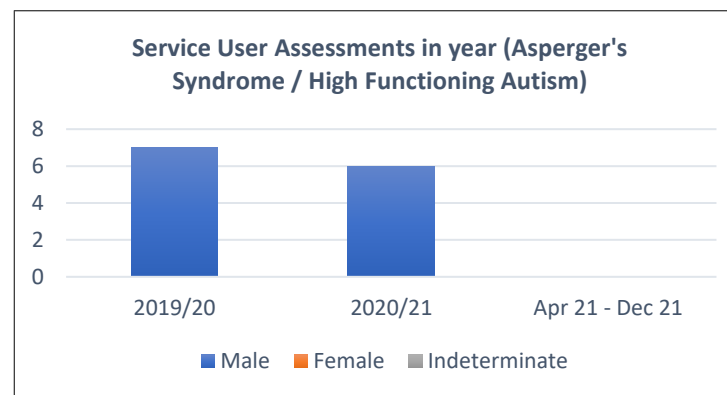
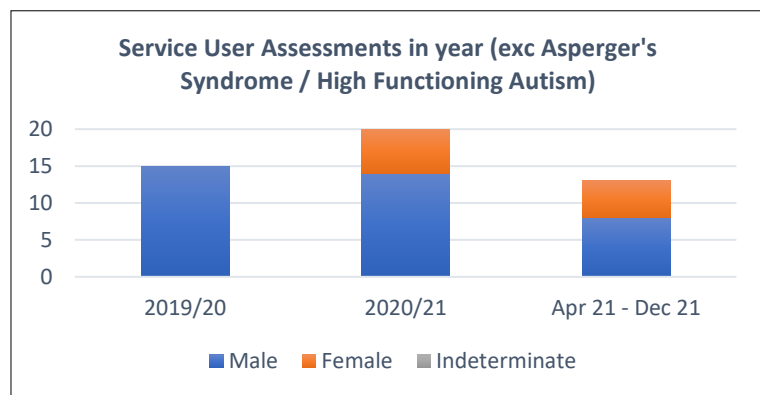


Figure 45. Service user assessments in year with Autism (excl. Asperger's Syndrome) and assessments with Asperger's Syndrome by Gender, Reading, 2019/20-Dec 2021

By age band, referrals in the first year for autistic people with Asperger's Syndrome/high functioning autism aged 65-84 is greater than any other group. There have been no assessments for 65-84 year olds between April 2021 and December 2021. (Counts in the previous years are too small to include)

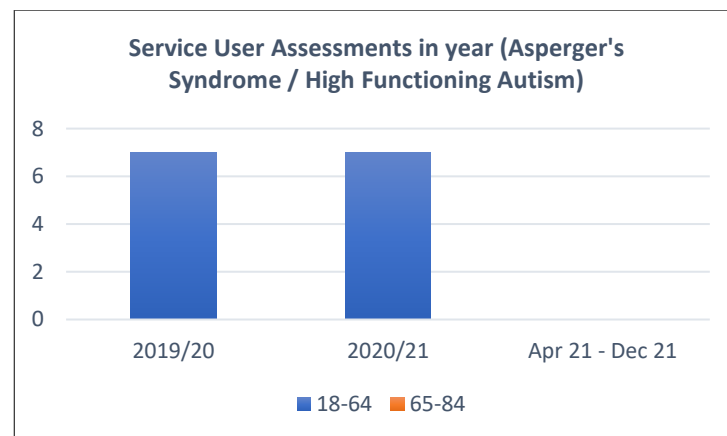
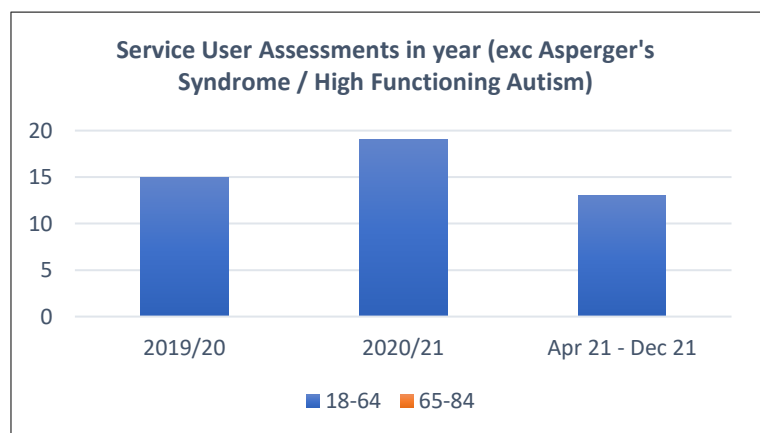
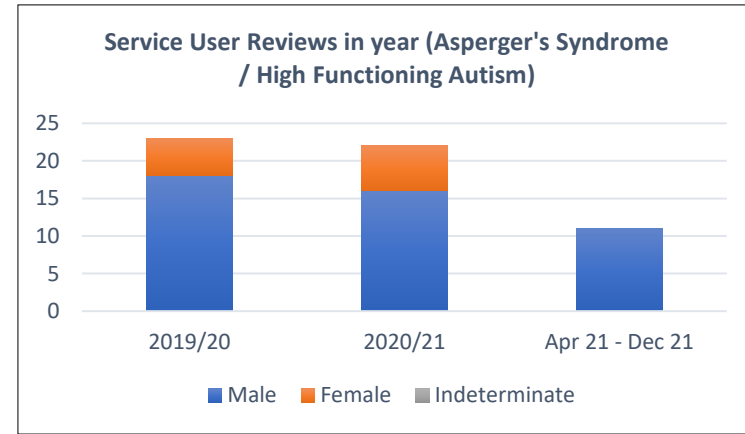
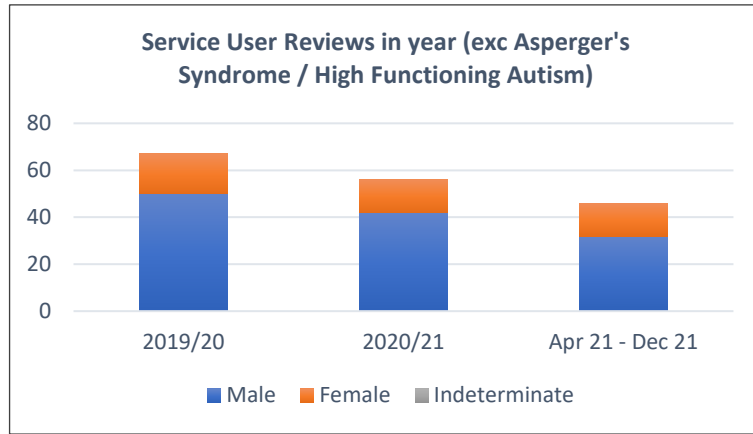


Figure 46. Service user assessments in year with Autism (excl. Asperger's Syndrome) and assessments with Asperger's Syndrome by Age, Reading, 2019/20-Dec 2021

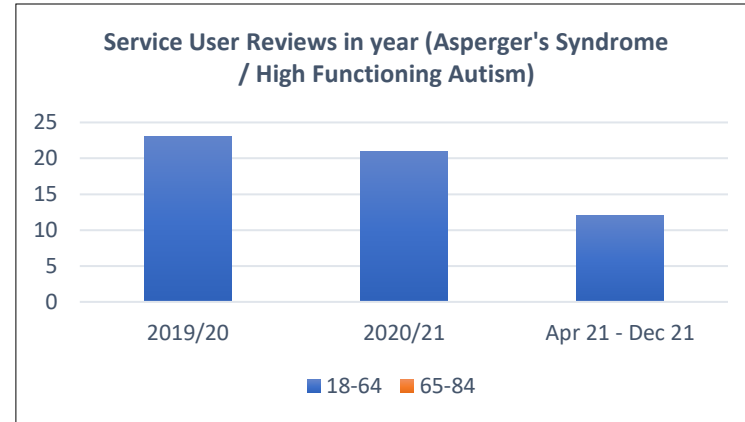
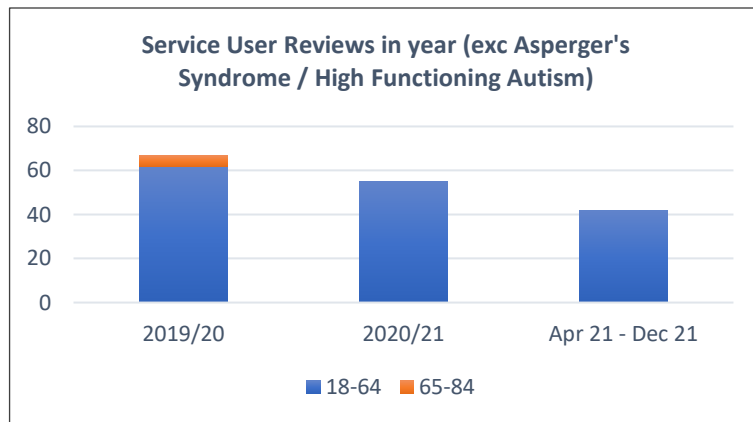
*Service users – reviews*

Numbers of reviews have declined across the 3 year period (noting that the third year is a partial year. The COVID-19 pandemic might have had a greater impact during 2020/21 which relates to the early stages of the pandemic when lockdowns and face to face contacts would have been greater. The 3:1 ratio of male to female appears to approximately in line, expect for autistic people with Asperger’s Syndrome/high functioning autism.



*Figure 47. Service user reviews in year with Autism (excl. Asperger’s Syndrome) and reviews with Asperger’s Syndrome by Gender, Reading, 2019/20-Dec 2021*

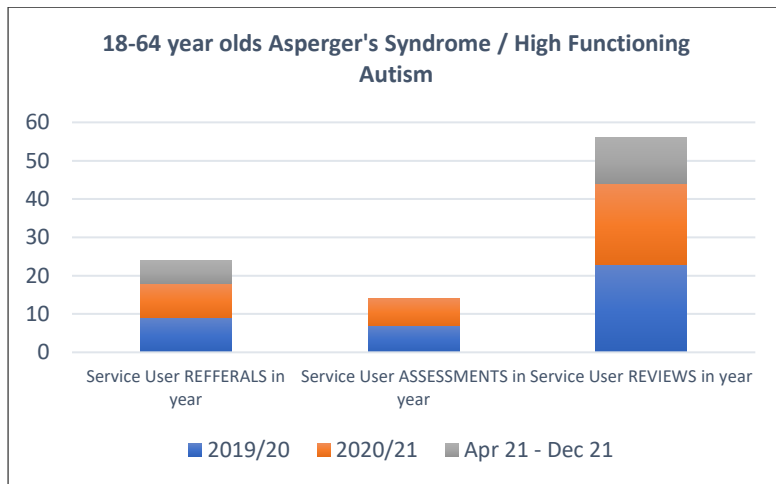
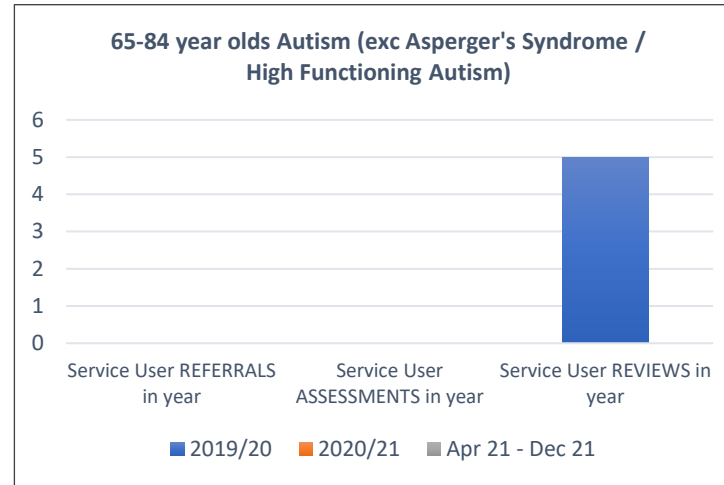
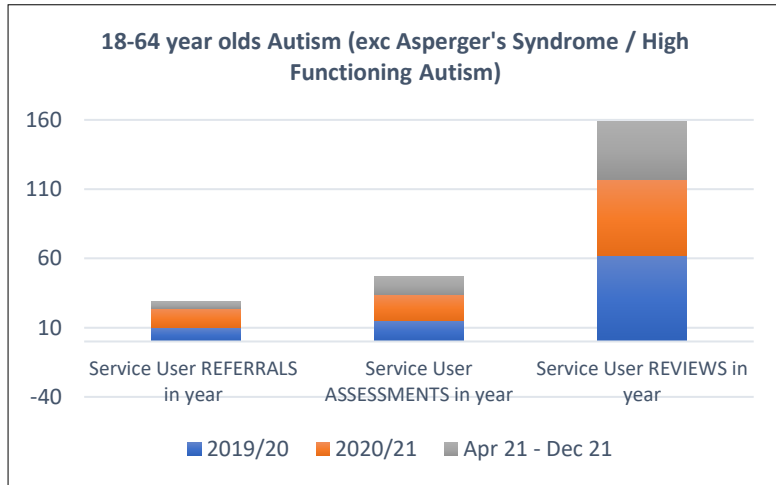
Likewise, the age band splits show a similar behaviour across all autistic people having reviews.



*Figure 48. Service user reviews in year with Autism (excl. Asperger’s Syndrome) and reviews with Asperger’s Syndrome by Age, Reading, 2019/20-Dec 2021*

*Comparing service users – referrals, assessment and reviews*

Bearing in mind the small numbers involved, there has been a relatively steady proportion of referrals, assessments and reviews year on year. Charts below show much greater activity around reviews, than either referrals or assessments. Reviews are 3 to 4 times greater than referrals and assessments, likely due to people having one referral/assessment but multiple reviews. To understand very low numbers within the 65-84 year old, knowledge is required around the time period when autism became more widely recognised and understood, and whether a diagnosis of autism would have been likely to have been made when this age group was in early adulthood.



**6.2.1 Recommendations**

One of the biggest issues is lack of data in Adult Social Care. This might relate to small numbers of autistic people using the system but mandatory and more detailed recording such as whether autism is a primary reason for using the system would aid confidence in the quality of the limited data available.

## 6.2.2 Training and Employment

### *Employment - Policy context*

There is recognition of the value of the development of independence and skill to support people to work and live to the best of their abilities in the Think Autism 2014, the most recent National Strategy for autistic children, young people and adults<sup>15</sup>, the Equality Act 2010, the Care Act 2014, the Care and Families Act 2014 and the NHS Long Term Plan 2019. These emphasise the importance of facilitating access to education, training and employment opportunities and sustained support, including skills development to help to empower people to independence wherever possible. The Equality Act 2010 highlights the importance and responsibility of employers of making workplace reasonable adjustments to support people with disabilities, including autism. The Care and Families Act 2014, highlights the SEND code of practice for people aged 0-25 years, requiring preparation for adulthood from the earliest years.

A focus on aiming to provide more opportunities for people with learning disabilities including autistic people is highlighted in the NHS Long Term Plan 2019, including increased targeted provision of supported internship opportunities.<sup>18</sup>

### *National Employment Levels*

Economic activity of people aged 16 to 64 years with a long-term health condition who mention autism as one of their conditions, by age bands, UK, year ending December 2020

### *Long-term conditions, Autism and Employment*

Respondents were first asked if they had any physical or mental health conditions or illnesses lasting or expecting to last 12 months or more. Only if they said 'yes' were they asked what conditions/impairments they had from a list, more than one condition/impairment could be chosen. 'Autism (including autism spectrum condition, Asperger syndrome)' was one of the response options.

Employment measures the number of people in paid work and differs from the number of jobs because some people have more than one job. The employment rate is the proportion of people aged from 16 to 64 years who are in paid work.

**Table 13. Economic activity of people aged 16 to 64 years with a long-term health condition who mention autism as one of the impairments/conditions, by age bands (UK, year ending December 2020)**

	Employed		ILO Unemployed <sup>67</sup>	
	Estimate %	Unweighted sample	Estimate %	Unweighted sample
16-19yrs	12.7	34	28.9	12
20-24yrs	27.3	57	24.3	18
25-29yrs	35.6	52	22.0	18
30-34yrs	37.8	32	10.1	5
35-64yrs	39.0	99	10.6	8
16-64yrs	28.4	274	19.3	61

	Economically active		Economically inactive	
	Estimate %	Unweighted sample	Estimate %	Unweighted sample
16-19yrs	17.9	46	82.1	248
20-24yrs	36.1	75	63.9	129

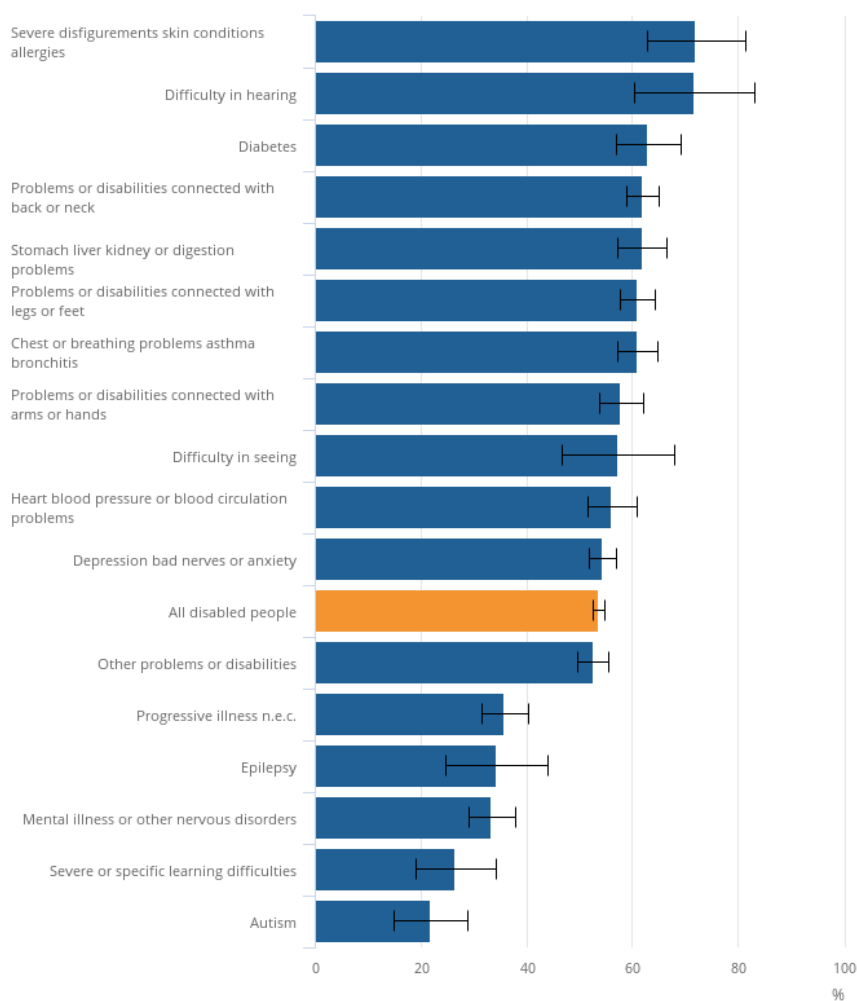
<sup>67</sup> Unemployed as a percentage of economically active. (Source: Office for National Statistics - Annual Population Survey)

25-29yrs	<b>45.7</b>	70	<b>54.3</b>	79
30-34yrs	<b>42.1</b>	37	<b>57.9</b>	59
35-64yrs	<b>43.6</b>	107	<b>56.4</b>	139
16-64yrs	<b>35.2</b>	335	<b>64.8</b>	654

The tables above show the economic activity of people aged 16 to 64 years, who state that they have a physical or mental health conditions or illnesses lasting or expecting to last 12 months or more and mention autism as one of their conditions/impairments.

### National employment levels – Autistic people

Estimates according to the Office for National Statistics (ONS) suggest that only 10-15% of autistic adults are in full-time employment and overall, 22% of autistic adults (16-64 years) are in employment (any form). Disabled autistic people (21.7%) were among those disabled people with the lowest employment rate.<sup>27</sup> They had employment rates which were significantly lower than the employment rate for the whole disabled population (53.6%) aged 16 to 64 years, and compared to 81% of non-disabled people, showing a significant employment gap for autistic people, which is of concern. Not only does this have an impact financially for autistic people, additionally, it contributes to them failing to benefit from a fundamental route to social inclusion and independence. Research-based and anecdotal evidence indicates that autistic people, although not all, want to work, are able to and would value support and awareness of pathways and available opportunities for employment.



**Figure 49. Employment rates of disabled people, by main impairment, aged 16 to 64 years, UK, 6 months year ending June 2020.** Disabled autistic people were among those disabled people with the lowest employment rate. Source: Office for National Statistics – Annual Population Survey<sup>27</sup>

Overall, nationally, significantly lower employment rates were seen in disabled people compared to non-disabled people, with highest rates seen in the South East (60.2% disabled people, 83.7% non-disabled people) and South West (57.5% disabled people, 84.2% non-disabled people).<sup>27</sup>

### *Employing autistic people*

Employers can benefit from a range of unique talents and skill that autistic people have such as (but not limited to); *logical and methodical approaches, problem solving, punctuality and reliability, exceptional attention to detail, creative thinking, strong technical skills (e.g., in IT) with some exceptionally talented and gifted*. Nevertheless, because of a lack of support and understanding, in relation to obtaining and keeping a job, autistic people are often disadvantaged.

Some of the most cited barriers for autistic adults wanting to be in employment include:

- Absence of effective transition from education
- Absence of reasonable adjustments at interview (anxiety inducing/distressing)
- Unsuitable HR practices e.g., standardised recruitment practices
- Inaccessible recruitment methods
- Absence of reasonable adjustments in workplaces
- Lack of employer awareness
- Difficulties accessing support to get into work or when in work<sup>68 69 70</sup>

These barriers are mirrored in the [The Autism Act, Ten Years On report](#)<sup>68</sup>. Although there is evidence of improvements in awareness of autism and confidence in recruitment of autistic people in employers, as shown by a YouGov poll by the National Autistic Society; there is still much work to be done with the poll reporting that 31% of employers surveyed stated that they needed additional advice on how to support autistic employees and that these employees would require too much support<sup>68</sup>.

There are significant pressures and challenges to maintain high levels of stable employment nationally, because of the COVID-19 pandemic impact on businesses and the economy, particularly as the furlough schemes have ended. The impact of this is a progressively competitive job market compounding the existing challenges for autistic people into paid employment. It is even more important that autistic people's needs are taken into account when developing and implementing actions around employment and support provision to prevent further widening the employment gap as a result of the pandemic.

For those unable to get employment, and requiring support to access benefits to ensure they continue to live independent lives, they find it challenging to access this support due to similar barriers around lack of understanding of the needs of autistic people; or autistic people finding it difficult to engage in the assessment process.<sup>68</sup>

Employer awareness is a key contributory factor in tackling many of the barriers mentioned, as awareness and acceptance will facilitate appropriate adjustments to environments, recruitment practices and the identification of adjustments required by employees

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<sup>68</sup> British Association of Social Workers (2016). The autism employment gap: Too Much Information in the workplace. [online] [www.basw.co.uk](https://www.basw.co.uk). Available at: <https://www.basw.co.uk/resources/autism-employment-gap-too-much-information-workplace> [Accessed Dec. 2021].

<sup>69</sup> Petty, S., Tunstall, L., Richardson, H. et al. Workplace Adjustments for Autistic Employees: What is 'Reasonable'?. *J Autism Dev Disord* (2022). <https://doi.org/10.1007/s10803-021-05413-x>

<sup>70</sup> All Party Parliamentary Group on Autism (APPGA) (n.d.). The Autism Act, 10 Years On: A report from the All Party Parliamentary Group on Autism on understanding, services and support for autistic people and their families in England. [online] Available at: <https://pearsfoundation.org.uk/wp-content/uploads/2019/09/APPGA-Autism-Act-Inquiry-Report.pdf> [Accessed Dec. 2021].



### What is happening 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.

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 College delivers adult education and can provide bespoke support for those with learning disabilities, including those with autism. New Directions College do not hold data on how many learners have autism. They record how many learners declare a need and what support they provide.

**Table 14. Training and Employment support provided in Reading**

SERVICE	SUPPORT PROVIDED
<b>Elevate Reading</b>	<p>The project is a co-located central hub for employment, education and training support for young people, including those up to age 25 with Special Educational Needs or who are care leavers. The Elevate project can help with:</p> <ul style="list-style-type: none"> <li>• Exam results support and planning next steps</li> <li>• Exploring career ideas and making choices</li> <li>• Choosing college or university options</li> <li>• Alternative training provisions</li> <li>• Support for job hunting including interview skills &amp; CV writing</li> <li>• Apprenticeships and job opportunities</li> <li>• Alternatives to Higher Education</li> </ul> <p>Elevate brings together traditional services, such as those provided by Jobcentre Plus, and wider support such as mentoring schemes run by the voluntary sector, and the Council's supported employment service for people with disabilities. This ensures that autistic young people can access tailored integrated support</p>
<b>JobCentre Plus</b>	<p>Autistic adults aged over 25 can access employment and training support through the specialist advisory service within Jobcentre Plus, and the Council's supported employment service. Reading JobCentre Plus provides personal support to help with preparing for work, finding training and applying for a job, as well as information about benefits through the Work and Health Programme <sup>71</sup></p> <p>There are 3 disability employment advisors at the JobCentre Plus covering the Reading area. Their work cover 4 main areas:</p> <ul style="list-style-type: none"> <li>• Upskilling work coaches</li> <li>• Enabling employers to interact with people with disabilities/anyone considered in law to have a condition that will have a bearing on their ability to work.</li> <li>• Working or engaging with partner organisations and employers to promote the disability confident agenda</li> <li>• Working with autistic people directly to support them into work</li> </ul>
<b>National Careers Service</b>	<p>National Careers Service provides information and advice to support adults and young people in making appropriate decisions on a full range of learning and work opportunities.</p>
<b>Autism Berkshire Benefits Service</b>	<p>Support autistic people into employment and work placements, including a Benefits adviser to help people claim benefits and deal with dismissal cases.</p>
<b>Optalis</b>	<p>Offers specialist disability and mental health awareness training to employers. The service also assists autistic people to obtain or maintain employment through the Supported Employment Model or Individual Placement and Support (IPS). We also provide bespoke travel training through our Ability Travel programme, and support to enter education, work experience or volunteering opportunities.</p>
<b>Graft</b>	<p>Provide 1:1 support to look at barriers to employment and packages of support to overcome these including online training. The service is for anyone age 19+</p>
<b>Ambitious about Autism</b>	<p>a charity that run specialist education services and employment programmes for autistic children and young people.</p>

<sup>71</sup> DWP Work and Health Programme <https://www.gov.uk/work-health-programme>

<b>Talkback</b>	Talkback offers a wide range of employment programmes that cater for all ages and abilities, comprising of training, through to work experience, supported internships and support to maintain paid work. We draw upon our experiences of working with autistic people to break down barriers that hinder access to paid employment. Talkback follow 5 key steps that enable autistic people to build real-world work skills and move closer to their employment goals
<b>Shaw Trust</b>	A well-established charity in the Reading for supporting people get into work through their mainstream Work Programme or specialist Work Choice programme.
<b>Scope</b>	Provides a 12-week employability support scheme for anyone with a health condition, including autistic people. The support is provided online (through Skype for example) and includes building a curriculum vitae, understanding the job market and doing mock interviews.
<b>Reading Mencap Family Advisers</b>	can support individuals with Learning Disability and Autism (LDA) who are already in employment when there are issues and also work with employers to understand how they can have a better experience of employing people with LDA.
<b>Ways into Work</b>	Provides support for people with disabilities to gain and maintain paid employment. Specifically, in Reading. They operate supported internships under the Route to Recruit banner with Activate Learning (Reading College), Brookfields School and Addington School and a variety of employers including the Royal Berks Hospital. They are setting up a supported employment cafe in Reading Town Centre which will provide paid work opportunities for people with disabilities as well as great coffee! This will be in conjunction with New Directions College. A project with Elevate (Reading Brighter Futures) will be supporting people who are struggling to get into work. The charity currently work with 57 people in Reading of whom 30+ have autism as a primary or secondary barrier
<b>New Meaning</b>	Supports with vocational pathways, tuition etc. to upskill children and young people and make many referrals to them and they support children with SEN very well.
<b>The Ways and Means Trust</b>	Offers work-based training for autistic adults, and adults with learning difficulties or mental health difficulties. The offer includes training, work experience and volunteering in catering, horticulture, warehouse work and cleaning.
<b>Starting Point</b>	Under the umbrella of the Mustard Tree supports with mentoring CYP with focus of reintegrating into school or employment etc. if post-16 and are an inclusive service.

There has been considerable disruption to the employment and training market because of the COVID-19 pandemic, and Reading's Economic Recovery Plan recognises the need to address the specific needs of autistic adults as we re-build the support infrastructure.

#### *Unmet needs and gaps within Reading*

Work needs to be done to improve in the following areas:

- There are limited options available for people over 25
- People once in employment have limited services to turn to if support is needed
- We need to bridge the gap between training and employment support
- Remove the current cliff edge when young people enter employment after 18+
- Support provision for late diagnosis for people already in employment
- Employers need organisations to go to for support and training

#### 6.2.3 Recommendations

- Ensure there is sufficient representation on the Autism Board to include providers of training and education, e.g., JobCentre+, Elevate & Reading College.
- There is more work to be done to close the gap between the employment rate for autistic adults and the general employment rate for the area.
- Employers need to look at their job adverts or their application process to make sure roles are clear and the application process is more accessible for people with special needs

- Role needs to be adjusted around the person so that the person can do the role – in the same way that adjustments are required by law for people with a disability
- Increase confidence to make first contact
- Simplify recruitment process and increase opportunities for autistic people to access employment
- Job interviews effective presentation – preparing for interviews
- Liaise with employer to better coordinate the Job application process
- Employers to understand and accept autism and make reasonable adjustments within the workplace or the role.

#### 6.2.4 Housing

Autism does not necessarily mean that a person cannot live independently, however appropriate support around housing choices and adaptations is of importance for housing outcomes for autistic people<sup>72</sup>. 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, however, anecdotal feedback captured through engagement with the Housing Needs team within Reading Borough Council that is discussed within this chapter.

There is no specific pathway for autistic people within the RBC 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 is predominantly awarded to young men aged 18-19 years old, and the service has been utilised to make adaptations for autistic people.

The homelessness service reports that there are 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. A lack of emergency accommodation through the adult social care pathway, and not meeting social care threshold are cited by the housing team as the key drivers for these emergency housing placements which may be inappropriate for the autistic individual.

It is recognised that many individuals may not meet social care thresholds, however some behaviours may lead to people being unsuitable for general needs accommodation. Accommodation options for this small number are very limited and are likely to lead to chaotic lifestyles, potentially resulting in rent arrears, eviction and homelessness.

#### *National picture*

The National Strategy for Autistic Adults, Young People and Children: 2021-26<sup>15</sup> prioritises housing as an area for improvement, to be achieved through a number of activities:

- 15 million of funding to put in place for keyworkers for children and young people with complex needs in inpatient mental health settings, as well as 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.

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<sup>72</sup> Autism Wales (2019). Autism: A Guide for Practitioners within Housing and Homelessness Services. [online] Available at: [https://autismwales.org/wp-content/uploads/2020/09/Autism\\_A-Guide-for-Practitioners-within-Housing-and-Homelessness-Services\\_Eng.pdf](https://autismwales.org/wp-content/uploads/2020/09/Autism_A-Guide-for-Practitioners-within-Housing-and-Homelessness-Services_Eng.pdf) [Accessed Jan. 2022].

- Commitment that 10% of the homes built via the £11.5 billion 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 will reach out to autism charities to raise autistic people's awareness of how the DFG can support autistic people.

### *Best Practice*

Housing for autistic people has no one size fits all solution but should be based on individual needs<sup>73</sup>. 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<sup>72</sup>.

Guidance produced by NHS England 'Building the right home' emphasises the importance of adaptations within homes. Alongside physical adaptations, geographical considerations should be made, particularly where there are sensory needs, e.g., housing away from noisy streets or bright lights and considering any triggers which could exist in the surrounding area<sup>73</sup>. Additionally, needs of the autistic person that may be linked to the proximity of established sources of support.

The Department of Health, the Local Government Association and NHS England asked people with a learning disability and/or autism and their families what is important to them about housing and what good housing should look like and is attached as an annex to the report. Key principles are detailed below:

Principles of housing for people with a learning disability and/or autism: "I have a choice about where I live and who I live with"

- be supported to live in their own homes in the community with support from local services
- be supported to live independently with the right support
- be offered a choice of housing that is right for them
- have a choice about who they live with, and the location and community in which they live. Things like access to public transport and social opportunities are very important
- have housing that works for them and meets their needs. They should not just have to move into a housing service or group living service just because there is space
- be offered settled accommodation. Includes aspects like people owning their own home and supported living
- be able to remain in their home even if their care and support needs to change. This means that the people providing care and support and the people providing housing should be separate so that a person can change who gives them care and support but doesn't have to move house.
- feel happy and safe in their home

*Extract from 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: LGA, Adult Social Services, NHS England (2016)*

A project and report produced by the National Development Team for Inclusion and coproduced by autistic people focusses upon adjustments that can be made within housing, viewed through the lens of autism as a sensory processing experience. Adaptations that are not costly and easy to implement such as sound proofing, information about fire alarm tests and LED lighting opposed to fluorescent lighting are all areas identified that could better meet sensory needs and improve wellbeing for autistic people<sup>74</sup>.

<sup>73</sup> 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](#)

<sup>74</sup> NDTi and LGA (2020). Supporting autistic flourishing at home and beyond: Considering and meeting the sensory needs of autistic people within housing. Available at: [Considering and meeting the sensory needs of autistic people in housing | Local Government Association](#)

As noted by Churchard et al (2019) there are no studies within peer-reviewed journals that test whether autism predisposes people to homelessness.<sup>75</sup> However, in comparison to those without autism, there may be increased levels of mental health problems, social isolation and difficulties with independent living conditions which are all known risks for homelessness. Within the UK, it has been noted that there is an increasing awareness that autistic people may face this higher risk, and the acknowledgment that an autistic person may be more vulnerable to abuse and violence. The [Autism and Homelessness Toolkit](#) recommends a number of approaches to working with autistic people who are homeless, including adjusting support to meet the needs of the person, and ensuring a consistent service is given<sup>76</sup>.

#### *Unmet needs and gaps within Reading*

- Housing services within RBC do not have support that they can access in relation to autistic people that approach for homelessness assistance that don't meet the criteria for adult social care. The lack of emergency housing options within adult social care may result in the autistic person being placed in accommodation such as bed and breakfasts which can be inappropriate and unsuitable for needs. This is particularly a problem for single autistic people.
- Training for front-line staff within RBC housing 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.

#### 6.2.5 Recommendations

- Support provision and housing for autistic people should be a priority for Reading; to enable autistic people to live in housing appropriate to their needs and for those who want to or have to live independently to receive adequate support be able to do so.
- Improved understanding of housing and accommodation needs is needed. As such, partnership work with local service providers is needed to develop/improve on data collection methods in their area of responsibility to enable consistent recording and analysis of the number of autistic people, their housing needs (among others) captured through the assessment process. These need to be considered in local housing plans.
- This information should be used as appropriate by service providers and commissioners to develop and improve services
- Data collection about housing needs should include projections of older adults and younger adults likely to have specific accommodation needs.
- Autism training is needed for housing staff and care providers to aid understanding of autism and facilitate reasonable adjustments to be made to ensure autism accessible housing processes, including promoting awareness and use of the Autism Toolkit.
- Joined up working with housing teams to enable autistic people to have a clear offer and pathway for housing access when required.
- Development of an autism housing pathway in partnership with Reading Borough Council Adult Social Care and local homelessness organisations to ensure needs are met and continuity of service is provided.
- Work with local emergency accommodation providers such as bed and breakfasts to improve understanding of autism.

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<sup>75</sup> Churchard et al.. (2018) The prevalence of autistic traits in a homeless population. Available at: <https://doi.org/10.1177/1362361318768484>

<sup>76</sup> Homeless (2019). Autism and Homelessness Toolkit. Available: [Autism Homelessness Toolkit.pdf](#)

## 6.2.6 Parents/carers

### *Families and carer support*

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 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 from other autism carers, and opportunities to take a break from caring. Carers have their own right to a Carers Assessment, which can be provided through social care or the Reading Carers Hub. This is often the first step in identifying what support would help the carer to manage their role and be able to take better care of their own health and wellbeing.

A range of voluntary groups and organisations in Reading support autistic people and their families. Autism Berkshire provides pre assessment and 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 support families one to one.

Reading has a good range of supported activities and short breaks for children, including autism specific activities run by Autism Berkshire, Engine Shed and short breaks funded by BFC covering different age groups. Some autistic children also access activities provided by Reading Mencap or The Avenue School Holiday Play Scheme for children with learning disabilities.

Two local third sector organisations - Autism Berkshire and Parenting Special Children – have been commissioned to deliver training and support for families face to face. There is an aim to reach more families and carers with the existing training offer to help give them the information and skills they need to manage caring.

Following an assessment, children with complex needs could be eligible to access overnight and daytime short breaks through Cressingham Short Break Provision. The Whitley Wood respite service is available to autistic adults. These services give families and carers a break from their caring role.

The COVID-19 pandemic and 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.

Tuvida Carers Hub is commissioned by Reading Borough Council and BFC to provide support to adult carers, including information, advice and guidance as well as respite breaks or crisis support with the Carers Break service. Parents and family carers can also access the Reading Carers Card, which allows carers to be identified at various local outlets for easier access and targeted support. Carers can also 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 the allocation of a personal budget specifically for the carer to use for an activity of their choice.

*Table 15. Number of carers looking after an autistic person supported by Tuvida Carers Hub as at December 2021*

Person cared for	Parent carers under 18	Adult carers
<b>Carers with Autism</b>	2	3
<b>Carers caring for someone with Autism</b>	61	25
<b>Carers caring for someone with ASD</b>	7	1
<b>Carers caring for someone with Asperger</b>	3	7

We recognise the need to review support for families and carers to ensure it is appropriate and sufficient.

### *Respite care in Reading*

Respite Care is a key area where provision is both inadequate and hard to access. Respite care, also called short breaks, is temporary care that enables carers to take a break. This could mean:

- help at home during the day, evenings or at weekends, sometimes called 'home care' or 'replacement care'
- support for individuals to do fun activities
- care overnight, either at home or somewhere else so that carers can sleep

Some people use the Direct Payments system to pay for a carer, managing the hours and paperwork involved. Typical amounts for Reading are 2-4 hours a week. Many families share that they struggle to access Direct Payments, despite having an autistic child requiring high levels of support, attending a special school, experiencing double incontinence or other key factors. Voluntary sector organisations that support families often have to advocate for families to be seen by a social worker and to be assessed for Direct Payments. This process can take a significant amount of time, for many months, often even years, and many families give up.

Direct payments when agreed also come with the added challenge of finding a carer who is available and skilled to support the autistic child/adult. The hourly amount of £10 and the small number of hours available mean that the roles fail to attract much interest. Buying into residential support is out of the price range of most people; this costs around £33 an hour, including overnight (e.g., local charity - The Chiltern Centre in Henley). So, a typical night away from 6 pm on a Saturday to midday on a Sunday would cost £600.

Residential opportunities in Reading are limited, and hard to access with a long assessment process and little availability.

When people have explored the residential services, they have often found them prescriptive and inflexible. For example, after going through a lengthy assessment process, families may be offered more than they need or are comfortable with (e.g., their child being away for 2-3 nights every 3-4 weeks). For many families this may be too much too soon, but they do need help one night a fortnight for example. It is not easy to leave, for instance, a young autistic child who may be non-verbal for several nights in a row but the offer has been reported to seem to be all or nothing. Many families have had to turn down support because it is not appropriate or sensitive to the needs of their child or to the needs of the family.

Clubs and groups are also confusingly called short breaks - activities where a parent/carer can leave a child. Some issues to highlight in relation to this are - the brevity of these sessions (on average 2 hours) mean that parents /carers typically wait around nearby for the child to finish the activity, so no break occurs for the parent/carer. Many of the short breaks are not appropriate for autistic children with higher support needs – e.g., children requiring supervision to stay safe, accompanying to toilets, among other needs.

The range of activities/themes of sessions has also been highlighted. Families have shared that a youth club type of activity where young people can just be with peers in a safe environment (not necessarily playing sport/performing) would be very welcome.

As is often the case, advocacy is typically needed for families to access quality respite care. For parents/carers for whom English is not a first language, those who struggle to understand the system, those experiencing exhaustion and / or mental health problems, the chances of accessing adequate support are reduced.

## *National picture*

There are an estimated 3 million family members and carers of autistic people in the UK<sup>77</sup>

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.<sup>15</sup> 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’ by improving understanding and acceptance of autism within society, improving autistic children and young people’s access to education and supporting positive transitions into adulthood, supporting more autistic people into employment, tackling health and care inequalities for autistic people, building the right support into the community and supporting people in inpatient care and improving support within the criminal and youth justice systems.

The Government has also pledged to provide funding 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.

## *Best practice*

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 (for example, carer’s breaks). 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 as well as the need to safeguard and promote the welfare of the child cared for. The Council must be satisfied that the child and their family come within the scope of the Children’s Act 1989.<sup>78</sup>

## *Unmet needs and gaps within Reading*

- A structured advocacy and engagement framework where parents and carers can voice their experiences and concerns and be reassured that they are being listened to and receive the appropriate level of support.

## 6.2.7 Recommendations

- Parents and carers need to be supported and feel supported at the outset even when a formal diagnosis hasn’t been made
- A systematic whole family assessment needs to be done once an informal diagnosis is implied to identify and address the needs of the carer as well as those of the autistic person.
- More structured and clear pathways support from school systems
- Facilitate Respite for families
- Look at increasing accessibility and support to resources and information for families and carers who do not have access to the internet, who do not feel confident coming forward to ask for information, or for whom English is not their first language

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<sup>77</sup> Local Government Association (LGA) (2022). Support for autistic people | Local Government Association. [online] <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>.

<sup>78</sup> National Autistic Society (2020a). Carers assessments in England. [online] [www.autism.org.uk](https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/carers-assessments). Available at: <https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/carers-assessments>.



## 6.2.8 Transport

### *Local Transport provision*

Reading has a vibrant transport system, with Reading Buses ranked as one of the most accessible in Europe, with colour coded buses and maps to help people easily navigate bus routes.

**Reading Buses** have worked closely with local charities such as Autism Berkshire, which led to implementing a driver training course to help staff learn about the needs of autistic people. With the help of Autism Berkshire, Reading Buses has been able to successfully raise awareness amongst its drivers about autism through ongoing training and actively providing support to autistic people for a better travel experience.

**Reading Station** is a major transport hub for Thames Valley, serving routes to London to Manchester, Wales and Cornwall. The station was renovated in 2014 to become more user friendly to users with additional needs.

On a yearly basis, the station has over 25 million passengers passing through it (2020 data).

Reading Station which is managed by Network Rail, offers an assistance service to passengers with additional needs, and this includes autistic people. Since July 2021, a new travel lounge has opened at the station for 'Passengers with additional needs'<sup>79</sup>

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.

Reading Station doesn't record data regarding the numbers of autistic passengers coming through the station, as this isn't something asked of passengers to declare.

### [Transport | Reading Services Guide](#)

There are various types of transport available to Reading residents who have special educational needs and/or disabilities. This includes council run services as well as private and voluntary sector organisations.

Brighter Futures for Children (BFfC) offer School Transport contracts to the companies that have applied to go on the framework (a mix of private hire/Hackney, O licence, S19 and school plated vehicles) and trained escorts are provided as required.

Readibus is the only specialist service used for School Transport – they are more for wheelchair pupils, but they provide 6 buses for the Avenue School – and an ambulance for 2 of the most complex needs pupils. There are 23 companies operating routes on the School Transport, there are a few other companies on the framework who haven't actually won any mini competitions to operate routes.

Around 540 pupils are on the School Transport scheme but there is no data about how many are autistic.

### *National picture*

The National Strategy for Autistic Adults, Young People and Children: 2021-26 gives transport special attention as a key enabler in helping autistic people become active members of society, through access to employment, leisure, and other community activities. The key commitment within the first year of the strategy is having an 'autism-inclusive' approach and includes:

- Continuing to promote a disability equality training package for transport operators
- Resume the 'it's everybody's journey' campaign to create a more inclusive and supportive public transport environment for disabled people.

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<sup>79</sup> Network Rail (2022). New assisted travel lounge opens at Reading station. [online] Available at: <https://www.networkrailmediacentre.co.uk/news/new-assisted-travel-lounge-opens-at-reading-station> [Accessed February 2022].

## Best practice

The Inclusive Transport Strategy<sup>80</sup> highlights 5 main themes that can be applied to an ‘autism-inclusive’ approach by transport providers:

1. awareness of passenger rights and enforcement – working to ensure that all passengers know what service they can expect and have the assurance that reporting non-compliance will lead to enforcement action
2. better staff training – to ensure that transport staff have greater understanding of the needs of disabled passengers and their legal rights, and therefore provide better assistance
3. improved information – so that information is provided in forms that all passengers can access and understand, both before and during a journey
4. inclusive physical infrastructure – taking steps to ensure that vehicles, stations and streetscapes are designed and built so they are inclusive and easy to use
5. future of inclusive transport – ensuring that new technologies and future transport systems are designed from the outset with disabled people in mind

The Reading Transport Strategy 2036 (draft)<sup>81</sup> incorporates the principles of the London Healthy Streets to develop walking and cycling as part of the Active Travel offer for Reading, including ‘providing shade, shelter and places to stop and rest’, ‘low levels of noise and air pollution’, ‘creating a sense of security’ amongst other goals.

The Reading Transport Strategy 2036 outlines some actions that can be applied to an ‘autism-inclusive’ approach for the Reading All-age Autism Strategy:

1. work with transport operators to deliver an accessible network for all, taking action to address barriers caused by physical infrastructure
2. continue to undertake Equality Impact Assessments...to enable us to deliver transport improvements that cater for all residents
3. continue to work with partners to deliver public transport...that is affordable and accessible to all and reduce inequalities in our communities
4. work with partners to deliver high quality, accessible, real-time data to assist users to make sustainable travel choices, recognising the differing needs of travellers

Many autistic people favour driving, walking and cycling as alternatives to using public transport which can sometimes be noisy, crowded and an uncomfortable experience for them.

### 6.2.9 Recommendations

- Expand on specific training to front line transport staff about autism and how to meet the needs of autistic people
- Consistency of transport escort staff or advance preparation with autistic child/young adult in mind, to anticipate and manage change

### 6.2.10 Criminal Justice System

Evidence is available, although mixed and limited, which suggests that autistic people are overrepresented within in the CJS in the UK. There is variation of estimates of the autistic people having contact with the CJS, with one study finding that 4.4% of the prison population was made up of autistic people, which if accurate is about for times the estimated national prevalence. Another 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

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<sup>80</sup> Department for Transport (2020). Policy paper: The Inclusive Transport Strategy – summary of progress. [online] GOV.UK. Available at: <https://www.gov.uk/government/publications/inclusive-transport-strategy/the-inclusive-transport-strategy-summary-of-progress>.

<sup>81</sup> Reading Borough Council (2020). Local Transport Plan Reading Transport Strategy 2036: Consultation Draft - March 2020.

autism within youth custody, and suggested an incidence rate of 15%. Overall, however, evidence is inconsistent but highlights overrepresentation<sup>82 83</sup>

There is evidence that autistic people often have challenging, poor experiences when they encounter the CJS as shown from the APPGA inquiry. Various reasons have been cited for this including a lack of awareness, confidence and understanding amongst CJS staff and challenges surrounding adjustments required for autistic people to engage in processes.<sup>84</sup> 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. Guidance developed by the National Autistic Society<sup>85</sup> is available, for police and professionals working in the CJS on how to interact with and facilitate better experiences for autistic people and their families' within the CJS. The National Autistic Society states that autistic people are more likely to be witnesses and victims of crime than offenders. An Autism and Intellectual Disability in Criminal Justice Network is available for people interested in autistic people that are in contact with the CJS or secure services<sup>86</sup>.

## Police

### *Processes that take place with the police when people are identified as autistic*

As part of the process when any person is booked into a Thames Valley Police (TVP) custody suite they are asked if they have any mental health conditions. As a result, autism is often not disclosed. Training has been initiated Force Equality, Diversity & Inclusion within the police, to help address this issue. Awareness training for all front-line Officers is planned for later in 2022 surrounding this, which the Police Autism Project Lead has consulted on.

The Autism Alert card has been rolled out with a strong partnership between TVP and Autism Berkshire and funding was made available from the PCC. With the permission of the individual, the card facilitates information sharing via Autism Berkshire to the Police. This information is then recorded securely on Police systems. The Autistic person can produce the card or their details which will allow the Police to access the information and with this information, make adaptation to ensure the interaction is more positive for those involved.

The role of the TVP Autism Project Lead is front line policing, focussing heavily on crime prevention, detection and providing initial support to those in crisis / at risk.

Within TVP, autism is not recorded in a meaningful way, making it challenging to generate reliable data. Anecdotally, it is reported that in West Berkshire alone, there is at least 1 incident day that is called in and involves autism in some way, shape or form. However, many incidents' police attend daily are not reported in relation to autism, however, it is often found that someone involved is either diagnosed autistic or undiagnosed. Still, there are challenges in quantifying this as no two days are the same in relation to demand, nevertheless, "**autism plays a part in police work on a daily basis, which is huge!**".

### *Gaps and recommendations from experiences of the police*

- Physical CJS related buildings are not designed to be easily adapted, however, some changes are possible with minimal effort and cost e.g., lighting / wall colours etc.
- Police are trained to deal with 'behaviour' and autism often affects how an individual behaves. This could lead to unnecessary arrests and inappropriate use of force.

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<sup>82</sup> Anckarsater H, Nilsson T, Stahlberg O, Gustafson M, Saury JM, Rastam M, and Gillberg C (2007) Prevalences and configurations of mental disorders among institutionalized adolescents. *Developmental Neurorehabilitation* 10: 57-65

<sup>83</sup> Katie Maras, Richard Mills (2021), Special issue on criminal justice and neurodevelopmental disorders: Editorial, *Research in Developmental Disabilities*, Volume 113. Available at: <https://doi.org/10.1016/j.ridd.2021.103923>.

<sup>84</sup> S.B. Helverschou, K. Steindal, J.A. Nøttestad, P. Howlin. Personal experiences of the Criminal Justice System by individuals with autism spectrum disorders. *Autism*, 22 (4) (2018), pp. 460-468, 10.1177/1362361316685554

<sup>85</sup> Criminal Justice - a guide for police officers and professionals. <https://www.autism.org.uk/advice-and-guidance/topics/criminal-justice/criminal-justice/professionals>

<sup>86</sup> Autism and Intellectual Disability in Criminal Justice Network. [www.autism.org.uk/professionals/others/criminaljustice/signup.aspx](http://www.autism.org.uk/professionals/others/criminaljustice/signup.aspx)

However, training planned for 2022, aims to address this and provide officers with information that will help them to assess behaviour differently.

- Awareness is poor but improving. There is still stigma and misconceptions associated with autism and ADHD which many officers still believe. Nationally, autism awareness is improving, and younger generations are more autism aware. Many interactions with Police or unnecessary force used as the last service of crisis as well as the interaction, is problematic for the officer dealing with it. The long-term goal is the eradication of stigma.
- More support from partner agencies is required as police often have no one to refer people to other than CAHMS and Adult Social Services.

### *Liaison & Diversion Service*

Liaison & Diversion (L&D) is a service 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 makes a proactive response to provide a diagnostic assessment service, to identify psychiatric and social needs. The service also links to treatment programmes for offenders and support to victims and family members. 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. Family and carers can also be supported where necessary.<sup>87</sup>

Assessments due to mental health, disability, or other vulnerability can happen while people are in police custody or at crown or magistrates' courts or outside court or custody. Support cannot be offered to those who are not involved with criminal justice (CJ), or if sentencing has already occurred. The service operates across the Thames Valley region but for the purpose of this needs assessment, the service provision in the Reading Locality will be the focus.

### *Referrals*

Individuals can self-refer or access the service by request at any custody suite or court. The service can be contacted once individuals have left custody or court. Referrals can also be requested by any professional including the police, court staff, and detention officers on an individual's behalf. L&D operates along the CJ Pathway and has main points of activity with TVP Custody Suites and Her Majesty's Courts and Tribunals Service (HMCTS). For Reading, these points are namely Loddon Valley Custody Suite, Reading Magistrates Court & Reading Crown Court. Within the custody and Crown Court, practitioners are professionally qualified and come from a variety of backgrounds. The multidisciplinary team (MDT) skillset includes Mental Health Nurses, Learning Disability Nurses, Social Workers, Speech and Language Therapists (SALT), support time recovery staff and peer support (staff with lived experience). Having a diverse and broad-ranging team allows the L&D service to support a more diverse and wide-ranging client base. Reading's learning disability nursing staff provide expert training on neurodiversity for staff regularly. One of the team's main role is identifying and assessing for neurodiversity needs and supporting reasonable adjustments in custody and court settings and then making onward referrals. There is a recommendation to enhance this provision as it is reported that most people that go to police custody from Reading go to Loddon Valley and as such enhancing support there would be beneficial.

L&D services aim to improve overall health outcomes for people and to support people in the reduction of re-offending. It also aims to identify vulnerabilities in people earlier on, which reduces the likelihood that people will reach a crisis-point and helps to ensure the right support can be put in place from the start. The main aspects that L&D services offer are identification, screening, assessment and referral to other services.

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<sup>87</sup> Berkshire Healthcare NHS Foundation Trust (2021). Liaison and Diversion Service. [online]. Available at: <https://www.berkshirehealthcare.nhs.uk/our-services/mental-health-and-wellbeing/liaison-and-diversion-service/>

<b>Identification:</b>	CJ agencies working at the Police and Courts stages of the pathway are trained to recognise possible signs of vulnerability in people when they first meet them. They then alert their local L&D service about the person.
<b>Screening:</b>	Once someone is identified as having a potential vulnerability, the L&D practitioner can go through screening questions to identify the need, level of risk and urgency presented. This helps determine whether further assessment is required.
<b>Assessment:</b>	Using a trauma-informed approach and approved screening and assessment tools, an L&D practitioner will undertake a more detailed assessment of the person's vulnerability. This provides more information on a person's needs and whether they should be referred on for treatment or further support.
<b>Referral:</b>	The L&D practitioner may refer someone to appropriate mainstream health and social care services or other relevant interventions and support services that can help. A person is also supported to attend their first appointment with any new services and the outcomes of referrals are recorded. L&D services will also provide a route to treatment for people whose offending behaviour is linked to their illness or vulnerability.
<b>Outreach:</b>	Multi-disciplinary teams, including Support Time Recovery workers (STR) and Peer Support Workers, will work holistically with people in community settings during the currency of any criminal proceedings, including addressing issues like housing and financial advice.

The police, probation and the judiciary make decisions based on the evidence and information presented to them. L&D services record all information about a person's health needs and, with the person's consent, share these with relevant agencies so they can make informed decisions about case management, sentencing and disposal options.

The service is an all-age service and all practitioners and STR workers will work with both adults and children. The service in Reading also employs one Youth Specialist Practitioner that operates an early intervention function and will pick up referrals from schools, pupil referral units, police school liaison officers, and other areas.

**Table 16. Individuals identified with Autism who engaged with the Liaison & Diversion service in Reading between Apr 2018 to Dec 2021.** NB: Data counts of less than 5 cannot be used for data analysis, therefore \* or no data might represent a count of < 5 and must be read with caution or be summed into a broader grouping.

	Engagement Numbers	Adults	Youths
Apr 2018 - Mar 2019	24	9	15
Apr 2019 - Mar 2020	67	44	23
Apr 2020 - Mar 2021	88	48	40
Apr 2021 - Dec 2021	48	13	35
	<b>227</b>	<b>114</b>	<b>113</b>

Referral Source	ADULTS			
	2018 - 2019	2019 - 2020	2020 - 2021	2021
	Apr - Mar	Apr - Mar	Apr - Mar	Apr - Dec
Court - Judiciary/Magistracy or Staff	*	*		
Identified by case id tool/screen/cell sweep	*	*	*	*
Other		*	*	
Police Custody (All Agencies)	5	35	45	11
Probation Service		*		*
Self/Family		*		

Referral Source	YOUTHS			
	2018 - 2019	2019 - 2020	2020 - 2021	2021
	Apr - Mar	Apr - Mar	Apr - Mar	Apr - Dec

Court - Judiciary/Magistracy or Staff		*		
L&D practitioner following initial screen	*			
Identified by case ID tool/screen/cell sweep	6	*	*	
Other		*		
Police Custody (All Agencies)	5	16	37	28
Self/Family				*
YOI or secure setting services		*		
Schools & Colleges	*	*	*	*
Children's Services		*		*
CAMHS/Other Health Service				*

## 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 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.

### Youth Offending Service in Reading

Reading Youth Offending Team (YOT) provided by Brighter Futures for Children (BFfC) comprises of an MDT team from different agencies who work with children and young people aged 10-18 years old to prevent them from entering the Youth Justice System for the first time or supporting them to prevent re-offending and helping them understand the effects offending behaviour can have on others and themselves. Referrals to the Youth Offending Service are made automatically by the police.

YOT get involved if a young person:

- |  |  |
|--|--|
| ✓ Has come to the attention of police or is arrested | ✓ Is convicted of a crime and given a sentence |
| ✓ Is charged with a crime & must go to court         | ✓ Is referred from Children's Social Care.     |

Potential outcomes resulting after a young person commits an offence include:

- |                                   |   |
|-----------------------------------|---|
| ✓ Youth Restorative Disposal      | ✓ Youth Rehabilitation Order for up to 3 Years            |
| ✓ Youth Caution                   | ✓ Detention and Training Order - Prison for Up to 2 Years |
| ✓ Youth Conditional Caution       | ✓ Section 91 - Prison for More Than 2 Years               |
| ✓ Referral Order for up to 1 Year |   |

### Support offered by YOS to young people on orders and cautions includes:

- |   |                                  |
|---|----------------------------------|
| ✓ Education, employment and training                                | ✓ Offending behaviour work       |
| ✓ Understanding the harm and helping young people repair the harm   | ✓ Communication support          |
| ✓ Reparation – paying back for the harm the young person has caused | ✓ Support from CAMHS worker      |
| ✓ Drugs and alcohol work  | ✓ Speech and language support    |
|   | ✓ Literacy and numeracy sessions |

## *Background*

The CAMHS Health and Justice team is a multidisciplinary team commissioned by the Clinical Commissioning Groups (CCG) to work in partnership with the 6 Youth Offending Teams in Berkshire to prevent offending and reoffending in young people. The CAMHS H&J sits within CAMHS. Health professionals in the CAMHS H&J team take referrals directly from Youth Offending Teams (YOT). CAMHS H&J work with young people on statutory orders as well as those referred for preventative work. They can see young people for the length of time that they are working with their YOT and pick up cases quickly and offer a timely and flexible service.

In Reading, the multidisciplinary team is made up of:

- Mental Health Practitioner
- Physical Health Nurse
- Speech and Language Therapists
- Clinical Psychologist/Team Lead with clinical oversight/specialist work

**Screening** – the CAMHS H&J team’s aim is to screen every new referral into the YOS. They will therefore check background information in their health system RiO and speak to caseworkers about their observations and checks. Based on this screening, they can then identify those young people that require further input which encompasses autism and special educational needs and disabilities (SEND).

Further input might include:

**Screening** – the CAMHS H&J team’s aim is to screen every new referral into the YOS. They will therefore check background information in their health system RiO and speak to caseworkers about their observations and checks. On the basis of this screening, they can then identify those young people that require further input which encompasses autism and special educational needs and disabilities (SEND).

Further input might include:

**Consultation** – this means that a YOS colleague will speak to the CAMHS H&J team about the young person or family requesting guidance or support with the case or signposting or liaison. In relation to autism, this might mean that they guide the caseworker on how to adapt their verbal communication, nonverbal communication and written communication.

**Assessment** – this could be a physical health assessment, SALT assessment, or the CAMHS worker might complete a mental health assessment, or an assessment of sexually harmful behaviour, violence risk to others or a cognitive assessment. Where the CAMHS H&J team have a strong sense that a young person has undiagnosed autism and a diagnosis would impact sentencing or intervention decisions, the team would contact the Autism Assessment Team and request an expedited assessment. This does not often occur (twice in 2021 in Berkshire).

**Direct intervention** – occasionally health professionals are asked to complete a direct piece of work for example: cognitive behavioural therapy, helping to complete an AIM3 (assessment of sexual risk to others), completing a SAVRY (risk of violence to others), creating a communication passport. The CAMHS H&J team’s direct input is more likely where social communication problems are suspected.



**Trauma informed approach** - some young people are identified as having complex needs that would benefit from a trauma informed approach. This approach is prioritised for young people with at least four or more adverse childhood experiences (ACE's) (such as neglect, abuse, parental mental health issues, parental substance abuse issues, parent's incarceration etc.) who are on a long order (at least 6 months).

In Reading it is reported that these young people with complex histories of survival, attachment and relationship disruption are often presenting with behaviours that are 'high risk' to others and 'high risk' to themselves as well as being 'highly vulnerable'. CAMHS H&J find that they are usually already known to a range of agencies and presenting as a challenge to each of them. In these situations' the team's role is often to lead multiagency formulations where representatives from each agency share the background and make sense of the young person's journey.

The team will consider the young person's story and what led to the behaviours being seen. They will consider the young person's developmental age and how to pitch interventions so that they are developmentally appropriate. They will think about the timing of interventions so that they are coordinated as well as think about who the key people are in building long-term sustainable relationships with the young person and family.

#### *Child and Adolescent Mental Health Services (CAMHS)*

The role of CAMHS in trauma informed cases is to offer clinical supervision so that the direct workers have a reflective space to think together. This is in addition to the existing professional meetings e.g., YOT risk panels and Child in Need / Child Protection (CIN/CP) processes. The aim of supervision is to support staff to be confident, emotionally resilient, and therapeutic. Most of the service's young people are not in the right place to receive Therapy and instead need direct workers that can form relationships with them. The relationship is the intervention – a relationship where mistakes are made but then repaired, a place to learn. These cases inevitably challenge the system at management level, as such there is often work required at this level to coordinate multiple processes and help agencies think together and avoid focussing solely on their own individual processes. This reduces the chance of professionals/agencies acting in knee jerk reactions that may put plans in jeopardy.

Many young people within the YOT population present with complex needs. Often young people within YOS who present with some 'autistic traits' are better understood as having complex needs and attachment difficulties, rather than, or, as well as autism. It's the complexity of the needs and the risks to others and self and from others that tend to take precedence in the intervention provided.

**Training** - all YOT health workers also offer bespoke training as required. This has included training on autism (e.g., identifying young autistic people, understanding how to tailor interventions, considering how to support the young person to navigate court and the CJS).

#### **Youth offending data – Local picture**

*Table 17. Reading Youth Offending Service Referrals, 1 October 2020 – 31 September 2021*

	<b>Number</b>	<b>Percentage</b>
<b>No. of referrals</b>	58	100%
<b>No. with autism diagnosis</b>	*	1.7%
<b>No. on autism diagnosis waiting list</b>	*	3.5%

NB: Data counts of less than 5 cannot be used for data analysis, therefore \* or no data might represent a count of < 5 and must be read with caution or be summed into a broader grouping.

During the period 1 October 2020 – 31 September 2021, there have been 58 new referrals into the Reading YOS. Of these one had a historical autism diagnosis and two were on the waiting list for autism assessments.

The Public Health Outcomes Framework (PHOF), April 2021, indicates that in 2020 there were **242.5 per 100,000** first time entrants to the youth justice system in Reading. This equates to 35 young people aged between 10 and 17<sup>88</sup>, only 1 of whom was autistic.

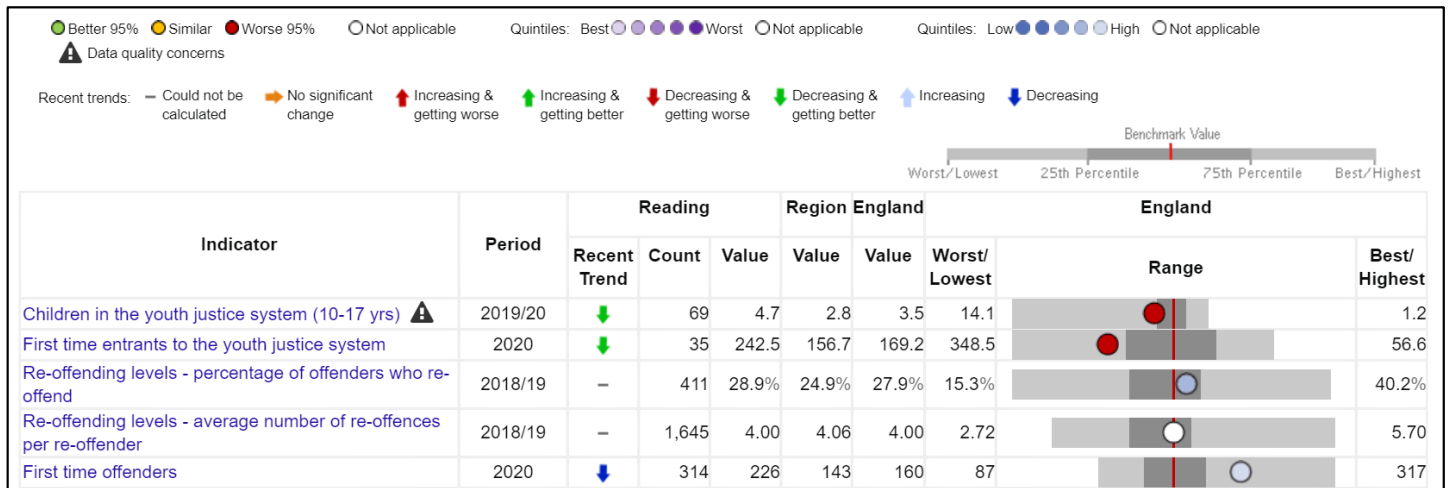


Figure 50. The Public Health Outcomes Framework (PHOF), Reading data on CJS

### Probation Service in Reading

The Probation Service is a statutory CJ service that supervises high-risk offenders released into the community and aims to reduce reoffending, support victims of crime, and keep the public safe, while supporting offenders to make positive improvements to their lives.

### South Central Estimated Figures (snapshot of total figures as at the end of September 2021)

In total there are currently **197** autistic People on Probation (PoP) recorded out of a caseload of **13,220**, representing **1.49%** of the caseload. However, there are gaps in recording of disabilities – **28%** of cases do not record whether a person has a disability. Of those recorded, **2.2%** are autistic, therefore, it is likely that the true number of autistic PoPs is slightly higher than the **197** that can be identified. If it was assumed that the same proportion of those with no recording are also autistic, then it can be estimated that there are approximately **290** autistic PoPs in total.

### Reading Probation Estimated Figures

Data is reported via probation delivery units rather than Local Authorities. As such figures reported are approximate. There are also some gaps in the disability declarations on the system used. Using the existing data and extrapolating this out, it is estimated that there are approximately **40** autistic individuals supervised by probation in Reading, of which approximately **10** are currently in custody and **30** in the community as reported on 7<sup>th</sup> February 2022.

<sup>88</sup> Office for Health Improvement and Disparities (OHID) (n.d.). Wider Determinants of Health - Data - Public health profiles. 2022. [online] Available at: <https://fingertips.phe.org.uk/profile/wider-determinants/data#page/1/gid/1938133073/pat/6/par/E12000008/ati/402/are/E06000038/iid/90848/age/211/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1> [Accessed Jan. 2022].

### *Probation - Regional Forensic Psychologist – Local input*

The Forensic Psychologist that covers Reading, is available to provide case consultation to the Probation Officer where there are concerns that the person on probation (POP) might be autistic. One Forensic Psychologist covers South Central Division (Oxfordshire, Buckinghamshire, Isle of White, Berkshire). Their role has contributed to the development of procedures for autistic people in Thames Valley, ensuring that responsibilities to make reasonable adjustments are actioned where necessary and guiding probation staff where necessary on how to work with autistic people through use of a screening tool and case consultation process where an autistic person has been identified. South Central probation have also devised a workbook providing probation staff with information on working with autistic people who have committed offences.

### *Neurodiversity within the CJS*

The Forensic Psychologist does not routinely get involved directly in diagnostic procedures but may only get involved if, in their professional opinion, there is a significant weight on decisions to be made that are dependent on the diagnosis.

### *Probation processes for autism*

**Where someone is diagnosed with autism:** Within the Offender Assessment system (OASIS), there are selection boxes to record whether someone has a learning disability or language requirement, however, there is no specific option for autism. It was highlighted that if this option did exist, it would still require the offender to state they had an autism diagnosis. In their current state, it was highlighted that the generic probation recording systems cannot be fully relied on. As a result, a study was conducted in 2016<sup>89</sup> on the prevalence of autistic spectrum conditions in a community offender sample from the Milton Keynes Probation office. This study's findings suggested that of the 336 offenders managed by a probation office that were screened for autism using the [Autism Spectrum Quotient AQ-10\) too](#)<sup>90</sup>, 4.5 per cent (15 offenders) of the caseload screened positive for autism. The study suggests that autism is not significantly over-represented in a large community offender sample. However, this is higher than in the general population - 1.1%<sup>52 91</sup>. Further research is required to identify the full degree of representation. There were limitations to the study such as the fact that demographic information on the sample could not be compared with norms across the whole probation caseload due to limitation of resources for the project.

**Where someone has a diagnosis of autism –** the Probation Officer can consult with the Forensic Psychologist. Occasionally, the Psychologist may meet the person on probation (POP) to do an assessment, however, this is not mandated. The Probation Officer will be provided with a copy of the Autism Workbook for people managed by HMPPS which supports staff to be autism informed in probation practice and offers guidance on how to interact and work with autistic offenders.

**Where it is suspected that someone might be autistic but has no diagnosis –** Some offenders within the probation service may have autism but are not diagnosed. The Psychologist completes the Adult Asperger Assessment (AAA) screening tool<sup>92</sup> with them. If they score above the threshold, they will require an assessment/diagnosis and are encouraged to seek this via their GP. As aforementioned, very occasionally and where there is a evidence that a rapid diagnosis might significantly impact on a person's community management – the Psychologist themselves will do a diagnosis if it is time sensitive to the

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<sup>89</sup> Andrew Bates, (2016) "The prevalence of autistic spectrum conditions in a community offender sample", *Advances in Autism*, Vol. 2 Issue: 4, pp.191-200, <https://doi.org/10.1108/AIA-05-2016-0014>

<sup>90</sup> Booth, T., Murray, A.L., McKenzie, K., Kuenssberg, R., O'Donnell, M. and Burnett, H. (2013), "Brief report: an evaluation of the AQ-10 as a brief screening instrument for ASD in adults", *Journal of Autism and Developmental Disorders*, Vol. 43 No. 12, pp. 2997-3000.

<sup>91</sup> Adult Psychiatric Morbidity Survey (APMS), 2007 (digital.nhs.uk)

<sup>92</sup> Baron-Cohen, S., Wheelwright, S., Robinson, J., & Woodbury-Smith, M. (2005). The Adult Asperger Assessment (AAA): A diagnostic method. *Journal of Autism and Developmental Disorders*, 35(6), 807–819. <https://doi.org/10.1007/s10803-005-0026-5>

circumstances of the offender. Otherwise, if a person doesn't have a diagnosis but there appears to be a need they are encouraged by the psychologist to speak to their GP to request assessment and diagnosis. It is reported that within the probation services, some people have the autistic traits but in fact personality disorder may be the more accurate diagnosis.

There is currently investment focussed on working more closely with autistic people as part of the planned Autism Support Service led by the Head of Community Reintegration in South Central Probation which plans to recruit a post to work more with autistic people in Probation with higher levels of need and support within the Thames Valley footprint.

**Prevent/Channel** - The aim of Prevent is to safeguard and support vulnerable people to stop them from becoming terrorists or supporting terrorism. Early intervention, identifying those at risk and offering support is key. Channel is a multi-agency approach to safeguarding, supporting and protecting children, young people and vulnerable adults at risk of radicalisation, extremism or terrorist related activity. Autism is recognised as a risk factor for radicalisation and nationally, a significant number of referrals to Channel are reported to be for autistic individuals.

#### *Unmet need and gaps*

A focussed Task and Finish group meeting provided feedback from partners including probation, liaison and diversion and the youth offending service on the interactions of autistic people with the CJS within Reading, alongside the core group. Feedback from partners around challenges autistic people experience within the CJS echoed the national picture and included a lack of general knowledge and understanding for professionals regarding autism, issues with training, reasonable adjustments and accessing social care support. Health partners also highlighted that there is a lack of appropriate provision within the community post secure system, and cultural and linguistic needs may also not be met within custody. It was also noted by partners within the VCS that autistic people have told them they have been targeted by people to transport drugs, and autistic black men have fed back that they are often stopped and searched, which can be a very frightening experience. In terms of recommendations to prevent offending and support rehabilitation and inappropriate involvement with the CJS, themes included early identification and support to prevent entry into the CJS, and better joined up working between agencies.

The CJS is not required to record autism as a condition. Therefore, only a limited analysis of the prevalence of autistic people was possible as there is no reliable data. Reading appears to be implementing key processes within its probation service that are beneficial in ensuring that reasonable adjustments are made to support autistic people that are known and ensure additional support is offered to them where needed thus reducing the likelihood of disparities between support and experiences within CJ settings between autistic and non-autistic offenders. L&D service reported that they were scoring low with identifying and recording support of autistic people. When reviewing amounts of clients coming through, it was a small percentage that were recorded of people with neurodiversity. It is reported that the database used language that was not appropriate in identifying neurodiversity and changes were made. Additionally, that autism can be a secondary need so a separate part for recording this could be made available on their database. 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. However, there are some gaps within the system to note. In prison and probation settings within Reading there is no probation lead which can result in a lack of ownership surrounding autism.

It is challenging to establish the actual number of autistic people within the CJS in Reading; however, this is not uncommon as other areas encounter similar difficulties. A comparative assessment was not possible as when gathering and analysing the views of professionals working within the CJS, it was highlighted that probation does not systematically screen for autism nor routinely hold or aggregate clinically reliable data or information on autism prevalence in their data systems. This appears to be the case within other CJS teams. Where data was available, it was

not considered to be clinically reliable or collected consistently and therefore could not solely be relied upon in providing an accurate picture of the prevalence of autism within Readings CJ setting. Noteworthy issues exist in recording of data on autistic people and there are notable gaps in robust data and information which is required to inform future strategies and direction. Although the actual number of autistic people are unknown within Reading's CJS, research and numbers reported suggest they are overrepresented within the system, as suspects, offenders, witnesses, or victims.

There is evidence of autism training available in Reading, however, no specific consistent training or delivery across the system. A workbook provided as part of the support offered by the Forensic Psychologist, is provided to probation staff however, this may not be used consistently as it is given where autism is suspected in an offender, so at present, there is no standard or mandatory training offer available for staff within the CJS.

### 6.2.11 Next steps and recommendations

This NA will feed into Readings Autism Strategy and aims to implement action to help reduce the numbers of autistic people involved in the CJS and provide multi agency support to those affected.

#### PREVENT

Many autistic people are targeted and thus become involved in crime, often not realising they are victims. This could be local criminals preying on the vulnerable up to Organised Crime Groups and or Extremists. Crime types include, but are not exclusive to, Cyber, County Lines, so called "mate crime" and Terrorism. Identifying those most at risk of becoming involved in criminality and working with partners to safeguard those affected is vital. Statutory Partners to include: Local Policing (Reading LPA), Counter Terrorism Policing and Cybercrime units. Areas such as terrorism have existing pathways which in the main are well recognised and known. Reading needs to build on these and ensure people are identified and referred appropriately. Less established, are pathways for intervention for those involved in county lines and other crime types. It is key to ensure that when identified, there are pathways for early intervention and support and processes need to be in place with the Police and other partners to work together to prevent people from becoming embroiled in crime. In effect, using safeguarding principles to provide tailored multi-agency support.

#### PROTECT

Ensure that as a Local Authority, our staff and partners (including Police) have the appropriate training in place. This, therefore, provides our staff with the appropriate specialist knowledge to be able to recognise when they are dealing with autistic people, to enable them to give the best possible service and understand the referral processes when applicable. Many autistic children are disproportionality excluded from school, meaning they are often home educated or placed in Pupil Referral Units (PRUs). Pupil Referral Units are being targeted by gangs as described in the home office report: [Ending gang violence and Exploitation FINAL.pdf \(publishing.service.gov.uk\)](#) Reading should aim to adopt a multi-agency approach with PRU's in the area to ensure they can provide a multi-agency safeguarding package for children at risk from these gangs. As a local authority we need to challenge more exclusions from school of autistic children and provide a multi-agency response for those at risk of exclusion.

#### PREPARE

Ensure Reading have multi agency teams ready to provide a support package to those already within the CJS, those who are on the periphery of being involved in crime and those effected by crime whether as an offender, victim or witness. Support Autism Berkshire and Thames Valley Police with the roll out of the Thames Valley Autism Alert card [Thames Valley Autism Alert Card - Autism Berkshire](#). Reading was a pilot area. The membership for Reading must be built upon.

#### PURSUE

Ensure we have systems in place to enable information/intelligence sharing with Law Enforcement so they can effectively manage their core role of bringing offenders to justice that prey on vulnerable people.

To improve the experience of autistic people in the CJS, key recommendations are:

- Expand the Autism Board to include a representative from Liaison & Diversion Service.
- Strengthen partnerships and joint working across the CJS and between agencies locally so that autism needs are recognised and met.
- To prevent offending and support rehabilitation and inappropriate involvement with the CJS, early identification and support to prevent entry into the CJS is vital.
- When dealing with autistic people, the officer in the case must consider whether arrest is both necessary and proportionate. The arrest of any child or vulnerable person needs to be carefully considered, however, there will be many occasions when the officer is not aware that they have arrested an autistic person and also occasions when arrest is the best course of action.
- 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.
- Use of and awareness raising of the Berkshire Autism Alert Cards to appropriate services such as the CSJ - a quick and easy way for autistic people of all ages, their parents or carers, to explain the condition quickly and easily to others.
- Implement adjustments throughout the CJS to create autism friendly communications and environments.
- Develop and improve systems that can record reliable data on autism and allow systems to cross share information to help provide a complete picture of a person's needs.
- Deliver further specialist training packages for employers, police and other frontline CJS staff to remove barriers and increase awareness, understanding and acceptance of autism.<sup>93 94</sup>
- Ongoing support to ensure training provided incorporates social interaction, social communication, sensory processing along with restricted and repetitive patterns of behaviours along with practical strategies for working with autistic people.
- Universal use of a consistent screening tool within the CJS is needed along with an information sharing protocol for information sharing between services.
- A clear social care pathway within the prisons in Reading and open social care referral process, which includes self-referrals from prisoners.
- Adaptations to custody suites, to make them autism friendly environments for when the arrest of an autistic person is necessary, as the environment can affect behaviour.

### *Training and Awareness Raising*

(In addition to training offered by other organisations)

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.

Within Reading's Brighter Futures for Children's Autism Advisory service, not only are all families supported in Reading that receive a diagnosis of Autism for their child through a range of methods including home visits and family seminars; but they work with various staff and organisations to raise awareness, understanding and support autistic people and their families.

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<sup>93</sup> L. Crane, K.L. Maras, T. Hawken, S. Mulcahy, A. Memon (2016). Experiences of autism Spectrum disorder and policing in England and Wales: Surveying police and the autism community. *Journal of Autism and Developmental Disorders*, 46 pp. 2028-2041, 10.1007/s10803-016-2729-1

<sup>94</sup> A. Tint, A.M. Palucka, E. Bradley, J.A. Weiss, Y. Lunskey (2017). Correlates of police involvement among adolescents and adults with autism Spectrum disorder. *Journal of Autism and Developmental Disorders*, 47 (9) pp. 2639-2647, 10.1007/s10803-017-3182-5

With action needed to reduce waiting times, and link people into appropriate support more quickly following assessment and diagnosis e.g., recruitment of additional Autism Advisors will be of value including raising awareness and understanding of autism across Reading.

**Autism Advisory Service Training and Awareness delivery - September 2020 – July 2021.**

NB. This is a term time only service

Family Involvements	131
Staff Consultations	54
Home Visits	22
Virtual Visits	138

*Parent Training Delivered*

Living with Autism 6-week Course - 4 delivered

*Staff Training Delivered*

<b>TRAINING DELIVERED</b>	<b>FREQUENCY/LENGTH</b>
<b>Norcot Nursery</b>	1-day virtual training
<b>BFfC staff October training</b>	Over 3 sessions
<b>BFfC staff November training</b>	Over 3 sessions
<b>BFfC staff training</b>	Over 3 sessions
<b>NQT training</b>	2 sessions
<b>Housing Team</b>	2 sessions
<b>School staff</b>	2 sessions
<b>Dingley</b>	2 hour workshop
<b>Parklane lunch time controllers</b>	
<b>Autism Network</b>	
<b>Redlands Intensive Interaction</b>	2 sessions

Since September 2020 the Autism Advisor has also begun the Intensive Interaction Co-ordinator training which involves weekly visits delivering Intensive Interaction.

The Advisor became the lead trainer for the AET project which so far has included extra training events and commitment to deliver AET training from September 2021 as well as supporting the Reading AET trainers.

Due to the COVID-19 pandemic, home visits have mostly been offered virtually this academic year.

	<b>Sep 16 - Jul 17</b>	<b>Sep 17 - Jul 18</b>	<b>Sep 18 - Jul 19</b>	<b>Sep 19 - Jul 20</b>	<b>Sep 20 - Jul 21</b>
<b>New Referrals</b>	193	167	203	130	131
<b>Home Visits &amp; Virtual visits</b>	140	156	133	84	160

## 7 | Stakeholder engagement

This needs assessment was built upon a co-production approach, using the input and insights from various key stakeholders from voluntary sector organisations, NHS and Clinical Commissioning Groups, statutory Children’s and Adult Services, Thames Valley Police and many others. Co-production has however, been limited due to no budget to actively involve all groups and service users.

Two Task and Finish Groups were set up:

### 7.1 The Data Analysis Task and Finish Group

The group provided a coordinated approach to work undertaken to address health inequalities in Reading surrounding Autism.

- The main task for the group was to support to develop an all-age autism needs assessment, to identify priorities/key recommendations, to improve local support for Autistic people.
- Priorities, key recommendations and the needs assessment will feed into the Reading All Age Autism strategy and subsequent implementation plans.

### 7.2 The Forums and Engagement Task and Finish Group

The group provided a coordinated approach to engagement and the establishment of engagement forums and use of existing forums, in Reading surrounding Autism.

- The aim of the engagement co-ordinated by this group informed the Reading Autism Needs Assessment and the All-Age Autism Strategy to follow.

A co-production approach was agreed by the Forums and Engagement Task and Finish Group with key stakeholders identified from the start of the project. Views of everyone involved were considered to design the needs assessment and its priorities with seriousness and equal value. To do this, we adapted to how people preferred to give their input, offering various options including:

Forums and Engagement Task Group	Responsible for ensuring co-production happens using members’ networks and contacts. Meeting online monthly and via email communication in the interim periods.
Community groups	Working with existing community groups who support autistic people – targeted approach.
Representation	Ensure that people with lived experiences, their families and carers from a variety of cultural backgrounds, language groups and age are represented and contribute.
	Ensure that people who support autistic people in all age groups are represented and contribute.
Accessibility	We want everyone to be able to have a say in the design process and this means adapting and offering communication support in accessible formats – easy read, large print, British sign language, printed versions, translated materials or support, emails or telephone if preferred

The participation and input from autistic people (children, adults, young people) as well as those who support them (parents, family carers, voluntary sector partners, professional and statutory services, commissioners) was actively sought through a series of focus groups and workshops, and a needs analysis survey. In total, we received views and contributions from **227** people from the surveys and the focus groups.



### 7.2.1 Surveys

Needs assessment survey	Number of respondents
Autistic Adults	23
Parents/Carers	88
Professionals	43

### 7.2.2 Focus Groups

Group	Date	Attendees
Talkback CAMEO	26/01/2022	9
Special United group	26/01/2022	10
Reading Autistic Families Together (RAFT)	12/02/2022	12
Compass Recovery College - Autistic adults	16/02/2022	6
Autism Berkshire Parents	27/01/2022	4
Engine Shed Session Children/Young people	29/01/2022	15
Reading Families Forum	03/03/2022	17

### 7.2.3 Additional feedback from key stakeholders

*Previous Stakeholder Engagement and Feedback from Children and Young People, and their Parents and Carers over the previous two years*

The following is the experience of families reported to the Forum and Stepping Forward.

#### Pre-diagnosis

Some schools have been excellent about identifying children who may be autistic and supportive while an assessment is made.

This is not consistent and, though support should be needs led, some schools have not put in support as there has been a dispute about whether a child is autistic or naughty.

Combination of Autism Growth Project by Deb et al and trauma informed practice should address this.

There is excellent support while on the waiting list for an assessment and families rate Parenting Special Children and Autism Berks highly. Not all parents know about this, though, and often turn to other parents and the Forum for answers such as what will the assessment appointment involve, when and how to explain the assessment appointment and any diagnosis to their child/young person. There is good advice and information on the BHFT website, but many parents do not know that there is more than just the criteria for referral etc.

OUTCOME – Families know where to get support while on the waiting list.

#### *Suggested actions*

- Publicise PSC/AB service even more and information on BHFT website – this is in the new SEND guide for parents.
- Ensure schools are reminded of the support available to share with parents
- A leaflet for those on the waiting list for an assessment would be helpful explaining where to get support, including social care, Engine Shed as well as the PSC/Autism Berkshire work.

It is important to manage parents and schools' expectations around what support a diagnosis will bring and what will happen after a diagnosis. Support to be needs led not diagnosis led and support can be accessed whilst waiting an assessment.

However, long waits and for a diagnosis are stressful for families – some are waiting for a diagnosis and are not happy with the support at school, waiting for confirmation whether their child is autistic, and some are concerned that they may be put on another waiting list at the end. General uncertainty is also a big issue. Not all partners, family, friends, school are supportive and can blame parenting, having an enormous effect on parental mental health and that of young people.

OUTCOME – waiting list is reduced to no more than a year

NEED – to be confirmed by BHFT

### *Post Diagnosis*

Young people were clear in the May 21 survey run by BFfC and RFF about the supports they would like on diagnosis – working group set up to look at how best to implement suggestions

OUTCOME – Recommendations agreed and implemented

Post diagnosis support from the Autism Adviser, PSC, Autism Berkshire, Reading Mencap Family Advisers and their adult services, Stepping Forward and TalkBack are all well regarded by parent carers. The Engine Shed and Raft are also well regarded.

### *Pre and Post Diagnosis Support – Social Care*

Parent Carer Needs Assessments and young carer assessments of siblings– parent carers have reported finding it difficult to get their needs recognised and supported. Some have filled out several forms and attend TuVida but the support from BFfC when following up on any actions from this is difficult to obtain. They would like clearer information about what they might expect and for CSPOA, Family Intervention teams and Early Help to have a better understanding of autism, disability legislation and their needs as carers and their other children's needs.

The information about parent carer needs assessments has recently been improved. RFF are in the process of writing a guide for parent carers about accessing children's social care.

Parents have reported feeling unsupported with their children's aggressive and/or destructive behaviour. Many have said that they feel unable to go out with their children due to their behaviour, including running off.

Families would like better support if their young person is incontinent. Some families receive little or no support in addressing this and costly incontinence pads if their child exceeds the allowed limit.

CYPDT had been updating their thresholds document as well as the threshold for children's social care in general, can we ask if a copy of this will be published for parents & professionals to ensure everyone is clear of the thresholds in order to access children's social care and, for some, CYPDT in advance of a carers needs assessment.

Jenna Redmond runs well regarded training to BFfC staff for some time now and will continue with this to develop understanding within early help and social care. All family workers and social care staff or anyone supporting children and young people can book a consultation with her to gain understanding and advice of strategies and support available for autistic children.

OUTCOME – parent carers feel supported in their role in caring for their autistic child.

NEED

- 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 with draws 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 CTPLD and children's social care are updated and publicised with parents and professionals.
- Work with incontinence service and OTs to improve support for autistic young people who may be incontinent.

OUTCOME – Brighter Futures are able to assess and act to reduce pressures of caring for an autistic sibling and the impact of physical aggression and emotional stress on them

NEED – training for social care teams on the impact on siblings and clear pathways when a sibling is experiencing physical and/or emotional abuse from their autistic sibling.

#### *Adult Social Care 18 – 25*

Parent carers report little planning for support when their child turns 18 and how much they are able to continue to care for their adult is sometimes ignored.

Parent carers also report that there is little planning for their autistic adult after college and at the end of EHCPs.

OUTCOME – young people leave college with either employment, training or social care support and parent carers have their wishes to continue care or not respected.

NEED - Planning for transition to adulthood includes long-term social care plans and the wishes of parent carers to continue to provide care need to be included not just the transfer of the case from children's social care.

Supported internships are excellent for those autistic young adults who are able to make use of this but young people but not all autistic adults can make use of these and there are very few alternatives. While there are some good opportunities coming up such as MakeSense Theatre and Chance to Dance, many young people end up at home with few meaningful activities or social opportunity.

OUTCOME all autistic adults have opportunities to either do training, paid work or activities outside the home.

NEED – develop further social enterprise and day activities with autistic adults.

#### *Education*

Some schools support autistic children well, but this is not consistent across schools. Training for teachers is being put in place with young people – Autism Growth Project

Transitions to primary school, secondary school and college are inconsistent with some really good practice and some less good. There is a working group looking at transitions to primary school led by Aimee Trimmer.

We hope that the roll out of the AET training will also support to improve transitions as all schools will have a better understanding of need.

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.

32% of autistic adults are in employment compared with 47% of disabled people and 80% of the general population. Latest figures are 22% autistic people compared to 81% of general population (ONS 2020)

**OUTCOME** – education staff across settings are skilled in teaching autistic children and young people and to improve children and young people’s attitude to their autistic peers.

**NEED** – Special United are producing a video on what they would like teachers and other professionals to understand about autism. Funded by Brighter Futures. Autism Growth Project is in place and training for children’s social care staff by the Autism Adviser.

### *Health Care*

RBH – carers want more information about the supports in place for autistic children and young people at the hospital, RBH are working on this. The Learning Disability Coordinators’ support is well-regarded but there is little in place for autistic adults without learning disabilities.

Autistic adults living apart from family carers struggle to attend medical appointments. This is supported by Mencap but need outstrips demand.

14% of autistic young people have felt suicidal compared with 0.5% of the general population and girls with ADHD are more likely to self-harm.

Locally, autistic adults and/or those with a learning disability are more likely to be admitted to a mental health bed than adults without autism and/or learning disabilities. Funding is being applied for to provide support when a young person is at risk of being admitted to hospital and BHFT are currently consulting families to improve their Crisis Response Service.

Families report difficulty getting support with their autistic child’s emotional wellbeing. Often their anxiety is dismissed as part of their autism and little, if any support for this is put into place. Many families have turned to the Forum for support and advice about getting support.

Children with Avoidant/Restrictive Food Intake Disorder (ARFID) have access to little support although special schools have developed skills in this area, there is little on offer in terms of specialist support.

Many autistic children and young people are fearful of medical procedures and needles. There is little support for these children and young people which leads to poorer outcomes later.

### **OUTCOME**

The long-term objective is to reduce the number of autistic young people and adults being admitted to mental health beds and for their general life expectancy to increase – actual targets to be developed based on BOB stats and their strategy.

### **NEED**

- Improve take up of Annual Health Checks, improve support for autistic adults to attend medical appointments, autism coordinator at Hosp? training for hospital staff in responding to autistic children and adults
- Develop support for children and young people who are fearful of medical procedures and needles.
- Develop more support for autistic children and young people with restrictive diets include Avoidant/restrictive food intake disorder (ARFID).

## *Housing*

Families and young people tell us that it is difficult to find information about what options are available and to obtain reliable, trustworthy 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, at a cost to their physical and emotional health.

### OUTCOME

Autistic young people have reliable options should they need or wish to live apart from their family carers. These options should ensure their physical and emotional wellbeing. Information is clear about those options.

### NEED

- Develop clear strategy for providing supported accommodation for autistic adults to ensure that are safe and reliable options for autistic adults that ensure their health.
- Ensure this information is communicated to young people and families

## *Criminal Justice*

The Forum has had little feedback from families except that a small number of black autistic young people have reported often being stopped and searched.

Families have reported being advised to contact the Police by social care if their autistic child or young person are aggressive to them. However, they have not wanted to do so, and when they have it has not been helpful in resolving the situation.

## 7.2.4 Conclusion

### *Suggested Priorities for Autism Strategy:*

1. Families and adults know of the (good) support available while waiting for a diagnosis and assessment wait times are reduced.
2. Parent carers and siblings are supported in their caring role and effective supports are in place if a parent or child is experiencing physical and/or emotional aggression.
3. There is effective planning for adulthood including social care after turning 18 and when finishing school/college if later
4. Autistic children and young people are supported to make the most of their education and reports of bullying and isolation are taken seriously.
5. Autistic adults enjoy good physical and mental health, with accommodation and access to health care two key aspects.

This should be in addition to the priorities of the Autism Growth Project

- Coproduction with children and young people
- Coproduction with parents and carers
- Establishing specialist resource bases in our mainstream schools
- Establishing a network of expertise and good practice across our educational settings
- Ensuring training is available for all educational settings and our partners across Reading
- Ensuring there are support networks for parents/carers across Reading

## 7.2.5 Feedback from Focus Groups

### *Parent and Carer feedback from focus groups*

#### *Education*

Main themes:

- Behaviour within schools can be misunderstood
- Schools may not implement their EHCP plans and policies
- Understanding of autism is still low

Education and school life were discussed by parents and carers at the Autism Berkshire focus group and at the Special United group. Participants told of anecdotes of their child's experiences at school, and the difficulties and challenges faced by both parents and carers, and staff. One parent spoke of getting constant phone calls each day about behaviour, as the school did not understand that it was linked to autism (Autism Berkshire parent). The child was eventually removed from the school by parents and placed in a different school. Another parent had a similar experience of school being problematic and had taken their child out of mainstream education to be home-schooled (Special United parent)

Other key themes coming from the sessions included:

- Continuity of teachers: within primary school there is one teacher, secondary there is several.
- Behaviour being misunderstood resulting in inappropriate disciplinary action
- Differing interpretations of meeting need, understanding of autism is still low
- An over reliance on schools to support both after diagnosis and awaiting assessment for autism
- Schools may not always implement their policies and EHCP plans, often are under-staffed and under-resourced

#### *Social Experience*

Main themes:

- **Bullying** and exclusion from social events is common and a significant problem for autistic children
- **There needs to be more inclusion and training for sports clubs**

Social experience was discussed by parents and carers at the Autism Berkshire focus group, key points are detailed below:

- Parent within the group's child has a limited number of friends and social interaction. They may see how they behave and feel different to peers.
- May not be fans of physical activity and fit in with 'norms' of sports clubs, can prefer computers, non-competitive activities.
- Sports clubs need to be more inclusive and coaches trained.
- Children can be excluded from birthday parties, sleepovers.
- Parenting Special Children run a social interaction club that may be helpful for making friends.
- Bullying is a huge problem for autistic children and is common within schools; Autistic children may lack the radar to figure out who is the bully. May be provoked by other children to provoke sensory overload, autistic child may then get in trouble for this. They can then be presented as the culprit for bad behaviour.

#### *Diagnosis*

Main themes:

- **There are long waiting times that can be problematic for parents**
- **Accessing support and information pre and post diagnosis needs to be improved. This should be clearly highlighted to parents and carers.**

Diagnosis was discussed by parents and carers at the Special United club, RAFT and Compass Recovery College ASD support group. A long wait for a diagnosis was spoken about by three of the parents, as demonstrated by one parent's experience: "My son was tested at five years old but I was told that he clearly wasn't autistic as he can speak, I waited 3.5 years for his ADHD diagnosis and now we're waiting once again for his autism assessment, It's been over two years. – I believed we were on the waiting list however I just recently got questionnaire to fill out about my son to find out if he's worthy of the waiting list! I don't know how much longer I'll have to wait." However, two parent carers spoke of a positive experience of the diagnosis process for example – "Had Council identify that my child had an issue and they were diagnosed very quickly because their behaviours were more obvious."

Parents also spoke of being unsure of the next stages once receiving a diagnosis, and where to access support. There were also mixed messaging about where to access support for a diagnosis, whether to go to health visiting, or speech and language therapy.

### *Post Diagnosis Support*

Main themes:

- **Support and awareness of autism amongst parents is not equitable**
- **There needs to be more understanding, awareness and compassion for autistic children across the education sector.**

Post diagnosis support was discussed by the RAFT parents group, key points are below:

- The post diagnosis support needs to be clearer and it is very important for parent to have care after receiving the diagnosis
- Difficulties around getting an EHCP in place with schools
- The group discussed how as a group they are educated, strong parents and they can fight and push for the children, consideration made about others who may have social issues, deprived, unaware; the system is not equitable
- Behaviour of others such as teachers is key, compassion and understanding is very important, a number of participants at the group agreed that some of the best teaching assistants are those with children with special educational needs.
- Training is needed for both teachers and other children on autism
- There needs to be more general awareness, to help break social isolation

One parent also spoke of their experience at a Private Nursery. At 3 years old they said something was 'off' with their child. The assessment was only done as older brother was autistic. The biggest issue was once they had the diagnosis at nursery nothing was done, the parent didn't even know what EHCP was.

### *Healthcare*

Main Themes:

- **Difficulties accessing and getting reasonable adjustments is still common for parents**
- **Post diagnosis support is not clear and there is limited information between referral and assessment for autism.**

Healthcare was discussed at Special United and the RAFT group by parents and carers. One parent at the Special United group spoke of difficulties getting the covid-19 vaccination for their

child – ‘Booking in the COVID vaccine, don’t want to have the vaccine in school but there are no referrals to hospital. Told there is a three month wait and they will call back. Similar experience with pre-school vaccinations, waited two years’. Another parent spoke of difficulty accessing reasonable adjustments for their child, sometimes two parents are needed for appointments, but this isn’t always allowed.

The RAFT group discussed that autism awareness has gone up significantly, but resources had gone down significantly, which was a big concern. They also discussed how health services were not accessible, you are often sent back and forth between different professionals and not much progress it made. One parent reflected that ‘It almost helps when you child has a secondary issue as you are at least kept in the system and get supported – because you can’t see autism, you don’t get much support’. Concerns around the period of time between referral and assessment, and healthcare included:

- ‘No communication in between time you fill in the form and the time you get an assessment – so you are just left waiting.’
- ‘Diagnosis – once received it is “see you later”’
- ‘After a huge wait and you finally get to see someone – the quality of support varies – we had an excellent SALT, poor on ADHD side who told us to research and chose the medication for our son. How would we know – they were the specialist. There is disparity between level of care’

### *Housing*

Main themes:

- **There needs to be consideration about the needs of the child when housed.**

The RAFT parents group discussed housing. One parent gave an example of a family who was moved into council housing with an autistic child. People who lived below them were complaining about noise, the child has sensory needs and shouldn’t have been place in a flat.

### *Autistic Adults Focus Group Feedback*

#### *Education*

Main themes:

- **School life and experience was a negative experience, and can have a lasting impact throughout life**
- **Lack of awareness and understanding of autism**
- **Connections service was helpful at the time (no longer exists)**

The Compass Recovery College ASD Support Group discussed education. Participants reported a negative experience, with school being described as ‘shockingly bad – 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’. Bullying was also mentioned by another participant - ‘I didn’t finish school due to the bullying I endured’.

Participants also spoke of the school having a lack of understanding - ‘My school never recognised my issues and dismissed me when I was struggling. I was told to ‘stop being anxious’ constantly.’ In terms of school helping to find work, two participants spoke of Connections (service no longer exists) and another stated they had no help at all.



Education was also discussed at the talkback CAMEO group. One participant cited that 'My experiences at school will always have an impact on me throughout my life. I can't just forget what the teachers used to say about my autism'

### *Social experience*

The Compass Recovery College ASD Support Group discussed social experience.

Main themes:

- **Being misunderstood and thinking behaviour is annoying were key concerns**
- **Better understanding and guidelines for employers around autism would be beneficial**

### *Employment*

Main themes:

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

Employment was a key topic of focus for the talkback CAMEO group. The picture below shows the key points that came from the group.



### *Diagnosis*

Main themes:

- **Long waiting times for an assessment**
- **Lack of support post-diagnosis**

Diagnosis was discussed at both the talkback CAMEO group and the Compass Recovery ASD support group. Both groups spoke of long waiting times to get an assessment - 'It took a real long time', 'I've been on the waiting list for a couple of years to be diagnosed'. One participant at CAMEO reflected that 'waiting for a diagnosis doesn't support or help people' and another

that they were in 'intensive therapy for a couple of years, the therapy was stopped to find out if I was autistic. It took two years for my assessment, so I went from intensive therapy to no help'.

### *Post Diagnosis Support*

Main themes:

- There is a lack of post-diagnosis support
- Social support would be beneficial post-diagnosis

Post diagnosis support was discussed at the Compass Recovery College ASD support group. A lack of support was cited, particularly where a person had been diagnosed through CAHMS - 'I stayed at CAHM's after my diagnosis at 16, in terms of getting support for autism was nothing. Got help for my other mental health problems but never about my actual autism.', another participant stating - 'I was told by CAHM's that their job is to diagnose autism, not support it.'

### *Healthcare Services*

Main themes:

- Healthcare services are not accessible for autistic people
- Annual health checks being made available for autistic people would be beneficial
- Reasonable adjustments at the GP surgery and when contacting the surgery are needed

GP surgeries were discussed at CAMEO and Compass Recovery as needing improvement in terms of reasonable adjustments, for example - 'having a different GP each time – start over and over again' and 'If you're panicking on the phone due to your ASD having the receptionist get angry at your stuttering from anxiety is really difficult and I avoid phoning the doctors'. One participant at CAMEO suggested that 'annual health checks should be made available for autistic people – could help set reminders for health needs'.

### *Housing*

Main themes:

- **Feeling comfortable and safe is very important**
- **Environment is important to consider**

Participants in the Compass group spoke of the importance of feeling safe within their home - 'Somewhere comfortable and safe' and 'I don't want to move out of my parents house, I like being there. I feel comfortable'. Another participant also spoke of maintaining their housing environment - 'I like everything to stay the same and I don't want to move.' Those at CAMEO spoke about 'having the right information about moving and what's involved' would support them with housing, and a consideration of the environment they are moving to e.g. remote location and building sites.

### *Local Services*

Main themes:

- **There are not many local services for autistic people**
- **Some services are not accessible because of music, lights etc.**

In terms of local services both CAMEO and the Compass group spoke about a lack of services for autistic people, one participant highlighted this was particularly the case for those aged 25-50. Groups that promote hobbies, skills and self-esteem were quoted as beneficial by a participant in

the CAMEO group. Some services may also not be accessible for autistic people due to the music and lights, however another participant in the compass group highlighted the 'autism hours' in some supermarkets.

#### *Autistic Children and Young People Focus Group*

Main themes:

- **Waiting time of for a diagnosis is very long**
- **Meeting strangers at the assessment is not easy for some young people**

Children and Young people at the Special United group reported that the waiting time for a diagnosis is very long - 'The waiting time was very long, this is the main problem, it is 1-2 years. It should be 3-6 months at the latest', 'The waiting list was very, very long – more than a year.' A young person also mentioned that they don't like meeting strangers, so they said the diagnosis process was 'not easy'

#### *Post diagnosis support*

Main themes:

- **There is not much support post-diagnosis**
- **Help with managing anxiety**

Post diagnosis support was mentioned at Special United. One young person said that they would have liked help with managing anxiety and what was happening next. One young person had been to Auticulate and it had really helped. They were very nice and helped with social conversations.

#### *Healthcare*

Main themes:

- Waiting times in the GP too long, appointments should be prioritised according to need
- Receptionists should be more aware of autism
- Need more time in appointments to get comfortable and process the information, need more time to ask questions

#### *Employment*

Main themes:

- **Employment was mentioned at the Special United Group by one young person, they said they 'were really worried about getting a job, about interviews and where to find a job.**

#### *Professionals Focus Group Feedback*

##### *Education*

Main themes:

- **Behaviour can be misunderstood and can result in children ending up in a pupil referral unit, and then potentially recruited by County Lines drug gangs.**
- **A lot can be understood through exclusions data within schools.**
- **There seems to be no accountability or recognition for disabled children within schools.**

## 7.2.6 Needs Assessment Surveys

### *Autistic adults' views*

A needs assessment survey was set up online between 31<sup>st</sup> January to 18<sup>th</sup> February 2022.

A total of 23 autistic adults responded to the online survey, with 4 reporting being under the age of 18.

The survey sought to get the views and experiences of autistic people focusing on Diagnosis and assessment; General health; Local health services; Housing; School life; Local services (other than health); Transport and Social experience and strengths.

The survey also gathered demographics data about age, gender, ethnicity, religious beliefs and sexual orientation.

### *Diagnosis and assessment*

#### Main themes

- **Long waiting times**
- **No support pre/post-diagnosis**
- **Going private was more efficient**
- **No support for mental health issues**

All respondents had received a diagnosis of autism. In addition to the diagnosis of autism, 30% reported that they had been diagnosed with sensory processing difficulties, 13% with dyspraxia, 4% with learning disabilities, epilepsy and visual or hearing impairment respectively, and 8% with obsessive compulsive disorder. Respondents further expanded on the additional health conditions they are experiencing, with the majority reporting they had anxiety disorder and depression.

Almost 48% of respondents (x11) received their diagnosis between 26-50 years old.

When asked if they had a diagnosis by a health professional, was the diagnosis process easy – yes or no - no one responded but 15 expanded on their experience, reporting that the **waiting time** was “very long” with some having to “wait a further 3 years”, “nearly 2 years” or even “five years”. 17% reported that they were kept informed about waiting times with 39% saying that the waiting time was more than 18 months.

People reported that they “found the **process inadequate**, clearly aimed at children, not adults”. One respondent said they were “repeatedly referred to irrelevant mental health services” and “GP needed to write several times to get referral through”.

In a few instances (x5) the respondent or their families had to seek **private assistance** for a diagnosis or assessment.

One experience showed that it “took around 6 months” to get the diagnosis and assessment done and that “it was very efficient”. However, there was “absolutely no **pre-diagnosis** for adults” and **post-diagnosis** “there is no useful” support available – 48%.

In one instance, the ‘parents were reported for abuse’ when in fact there was a lack of “understanding of the causes of anxiety” by professionals.

A couple of respondents said that they were “referred by Talking Therapies” as their GP were not able to “GP didn’t believe I could be autistic”. This was also the experience of another respondent whose “social worker laughed off the idea” that they were autistic.

A female autistic adult reported that “the diagnosis process via the NHS is...a joke” and that she was “unsure...” she “will be taken seriously” because of being “a woman and presenting less stereotypical symptoms”.

In one instance, the respondent has “been tested for multiple different disorders but never ASD” whilst being transferred between CAMHS and Berkshire Adolescent Unit over a period of 4 years.

One respondent reported that they were “not allowed mental health support because as they were on the ASD pathway” and were told that mental health services “do not support people with ASD”.

The experience of going private was “clear and concise”, “quick” and people felt “looked after”.

When asked about their experience of the assessment, only 1 person responded that they “found the assessment adequate”. 10 respondents expanded on their experience highlighting “serious misunderstanding” from clinician, “no signposting for further support” and “how to manage the condition” for the autistic person, their families or carers – “child has to learn to self-manage and the family has to support”. One respondent found by themselves support from a local voluntary organisation, “officially there was nothing”.

Only one respondent said “I was offered some support” through the Hospital Patient Liaison service.

### **General health**

To the question, how would you describe your general health, a majority – 48% - reported being in Good health, with 30% reporting as Just OK.

17% of respondents said they had poor or very poor health, citing as main health concerns ME, chronic pain, depression and anxiety, severe insomnia, fatigue.

#### *Local health services*

##### Main themes

- **Access to local health services could be improved or adjusted**
- **Reduce the need to make appointments by phone**
- **Better awareness of what autism is and environmental/sensory impact on autistic people**

To the question, how accessible are local health services for autistic people, 52% responded that ‘local health services are not very accessible’, with 22% raising that they ‘don’t know what local health services are available for autistic people’.

15 respondents provided suggestions for reasonable adjustments to access local health services (such as local GP surgery). They include:

- “Quiet waiting area(s) away from other people and with low traffic”;
- Educate the nurses in the hospitals and GPs about what Asperger is, about mental health in general and what other support services are available in the community (Compass Recovery College, AutAngel). “The NHS is great at dealing with physical illness but abusive to those with mental health issues;” staff tend to have certain views about autism which aren’t helpful and don’t realise all autistic people are different”
- Review appointments systems to make it more easily accessible for autistic people – “It is hard to use a phone”; “Too much reliance on phone calls”; “many autistic people find it difficult [to use the phone], so need an alternative means of messaging”; “I can’t face making the phone call [for an appointment]”
- “Not enough services, especially for mental health needs”
- “Services carry out a ‘one size fits all approach’ rather than a more specific ‘case by case’ approach which is essential in this context”
- “Notice of things like fire alarm tests”
- Consider the needs of “medium to high functioning autistic people<sup>95</sup>” so that they are not “completely forgotten with little to no support”

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<sup>95</sup> **A keynote of terminology/language used.** The report is structured as is typical for a Needs Assessment in Public Health. It is acknowledged that different people have different views on terminology relating to autism. In this instance, we have kept the term as per the feedback received for transparency and accuracy.

## *Housing*

### Main themes

- **Home needs to be within easy reach of transport routes, local amenities**
- **Quiet and safe area and environment**
- **Close to additional support networks**

To the question, what type of housing do you live in, a majority of responded that they own their home (48%) with 35% living with family or renting (from the Council or from a private landlord) respectively.

Respondents described an ideal home 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 “well insulated, easy to ventilate”, in easy reach of support such as ‘housing officer’, ‘parents’ and where there could be a “friendly point of contact” for “repairs, money management” for example. “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”.

43% of respondents said they would want to live on a bus route with 26% opting for a remote area. A further 8 respondents expanded on their preferences saying they would prefer being within “walking distance” to “shops and amenities” or to a “bus route”, “a main railway station or underground metro station”.

When asked if they requested help to find a safe and comfortable home, 48% responded that they didn’t, with 39% selecting ‘Not applicable’ as a response. Only 2 respondents had requested help to find a safe and comfortable home, citing support from Reading Borough Council to move to “an appropriate accommodation in a quiet area”, and support from “MySafeHome.info” but this service “is no longer available”.

## *School life*

### Main themes

- **Difficult experiences during school life**
- **Need to raise awareness about what autism is and is not and how to meet the needs of autistic people within the school and workplace environments**
- **Insufficient support and signposting after completing school or to enter into employment**

When asked what **type of school** they attended, 74% responded that they attended a mainstream school without additional support, with 17% attending a mainstream school with additional support and only one autistic person being home schooled.

On experience of school life, 74% reported that they didn’t receive the support they needed throughout their schooling, with only one respondent saying that they had.

10 of the respondents expanded on their **experience of school life**. They mention a “lack of support for therapy sessions which was crucial to make progress towards independence and education”, ‘toughing it out’, not being able to “manage the day-to-day struggle of being in a large environment without having someone to talk to about how difficult being in a large class was”.

A student on the high performing autistic spectrum was “removed from SEND register because all based on whether the student is strong academically”. Although “top of the year...could regress at any point...and suffers in busy, noisy classes daily and has anxiety all the time, but manages it himself”, but no support was provided by the school.

An experience related to being “treated as if [being] learning disabled” which resulting in a lack of “any decent sex-education, or education on World History, World Religions such as Islam, Economics and Geopolitics”.

One respondent experienced “bullying” and had to be “pulled out of school” due to mental health, “pressure of school as well as how they were treated by their teachers”.

Through New Directions College, one respondent who had been home schooled was able to complete their GCSE’s.

After completing school, 30% responded that no support was available with training, further education and work choices. 21% responded that support was available but there was no autistic spectrum guidance. There were no responses that support was available which specifically addressed issues related to autism.

26% said that there was no support to enter employment with no responses to the option ‘support to enter employment was available’.

8 of the respondents expanded on their choice of response and experience citing that they “didn’t know” of their condition at the time. The options given were “to go to college to do GCSEs, get a job in a factory or shop, or help with University application forms”.

Of those who had received support (21%), 9% said that the support was good and comprehensive, however 26% said that the support was poor and difficult to access.

10 respondents expanded on this point and their experience, citing the need to “ask questions” to the tutor at a leading College “on a one to one basis on what couldn’t be understood in Tutorials”, “it was a long drawn out nightmare...extremely difficult”. Instead of being offered to “tell what you can do”, one respondent cited that they were “always told instead what they cannot do”, ‘it was making finding a job harder”.

#### *Local services (other than health services)*

##### Main themes

- **Limited range of community activities for autistic children, young people and adults (incl. activities for female adults)**
- **More trained support workers to run activities in the community**
- **Raise awareness about what autism is and is not**
- **Need to adjust environments where activities or services are delivered from to minimise sensory impact**

When asked about local services for autistic people, 87% responded that they thought there is only a limited range of services in this area that consider the needs of autistic people, and a lot of improvement is needed.

19 respondents expanded on this topic and offered some suggestions on what changes would make it easier to use local services more.

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”.

Some local services are used and easy to access – AutAngel was mentioned as an example, with their offer of ‘Exploring Being Autistic’ course and peer support groups, Craft group.

Also mentioned are 197 Social Group Autism Berkshire and Compass Recovery College Social Groups, Taekwondo and Karate Clubs, Rivermead Gym, Martial Arts, Berkshire West Autism Services.

Some suggestions given were for

- a “greater levels of understanding of Autism” from some activity instructors and “greater recognition of individual needs from some Autism services”
- “groups for non-men, 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)”
- “soundproofs rooms” in hairdressers and beauty salons for a “relaxed sensory experience”
- “Fitness classes and social groups aimed at autistic people”

Wheelchair access was raised as a main issue from one respondent, citing barriers such as “kerbs, potholes, lack of ramps and turning space indoors”.

“Reliable online info about opening times, busy times, and mask requirements. No need to phone.”

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 “non-existent”.

### *Transport*

#### Main themes

- **Using public transport – in particular buses – is a stressful experience (crowded, increased sensory impacts)**
- **Trains are good and support is available**
- **Walking, cycling or driving as alternatives to using public transport**

When asked about experience of transport options available, 22% of respondents found it stressful or a cause of anxiety, with no information or support, with 13% needing additional support with transport and 13% finding that staff are helpful and there is support and information.

13 respondents expanded on their experience of using transport, with x4 saying the experience was “stressful or made them feel nervous”. A couple of respondents mentioned biking and train as “fine” options and choosing to walk or drive instead of “being in close proximity with other people”. One responded told of their experience of using buses as “confusing...and can only be managed accompanied by somebody familiar with the routes”.

One respondent said it is “very difficult with a wheelchair/scooter”.

On a positive note, a respondent mentioned that “simple train journeys are the best and the staff are generally pleasant and helpful” and that with getting older they have “found public transport easier to cope with”.

When asked what needs to be done to improve on the experience of using transport services, 11 respondents gave some suggestions such as

- “less roads more trains”
- “better cycling integration”
- “more detailed information available generally”
- “bus drivers could exercise greater care and manners” and “bus staff need to be trained”
- “autistic people need access to bus passes with extra support needs printed on it, even if it has to be paid for – preloaded with ‘x’ amount of trips”
- “temporary blue badge scheme”
- “joined up national transport strategy”
- “additional support of getting driving licence for people with anxiety and sensory difficulties”



### *Social experience and strengths*

#### Main themes

- **Mental health support is a priority**
- **Support to navigate information, advice and guidance on a wide range of topics**
- **Raise awareness about what autism is and is not and how to meet the needs of autistic people**

When asked about concerns affecting autistic people, the following areas were cited in ranked order:

1.	Access to mental health support	91%
2.	Access to support groups	87%
3.	Social inclusion or acceptance	83%
4.	Employment opportunities and support	65%
5.	Experiences of bullying and discrimination	61%
6.	Money and finance	52%
7.	Physical health and support	48%
8.	Home and moving out of the family home (autistic appropriate living)	26%

To the question what needs to be done to address these concerns, 16 of the respondents contributed the following suggestions:

- “A lot more funding for valuable autistic-led organisations that are providing support for autistic adults (especially those with later diagnoses) and that are inclusive of diversity”
- “better integration between assessment/diagnosis and service provision”
- Support to “navigate the range of services and providers covering all the various needs (mental health, employment, social inclusion) due to the complexity”
- Statutory services such as “Teachers, social services, medics, counsellors, the police” and Employers... “all need to learn about autism without intellectual disability”
- “Different support groups for different age groups not just adult / child / parent split”
- “Mental health support needs urgent attention” for autistic people
- “Clearer information on where to find support”
- “More financial support for disabled people”
- “More integration of health services (e.g. ensuring that CMHT and physiotherapy are autism aware)”
- “flexible supported independent living that can provide support specifically where needed while allowing as much independence as possible”
- “Access to Work support and some reasonable adjustments are not enough” – the “general public” needs to be “sufficiently educated about autism and its impact on our health and everyday functioning” to dispel “misconceptions and misunderstandings” i.e. in school environments”

Finally, respondents were asked what they were most proud of and what are the strengths of autism. There were 18 contributors in response to the question:

- “Think constructively”, “logic and problem-solving abilities”
- “My individuality”
- Raising a family and running a house with two kids “despite not being aware of being autistic”
- Achieving well in sports and education
- “strong sense of morality and good attention to detail”
- Being “full of wonder and curiosity”
- “creative side of our brains” and “seeing the world in a different light”

### Demographics

- Gender: a majority of female (48%) responded. Male respondents represented 35% and 4% self-described as Trans Non-binary.
- Age group: the majority of respondents were in the 25-34 and 45-54 age brackets, both at 22% response rate, closely followed by 35-44 and 55-64 age brackets both at 17%.
- Ethnicity: the majority of respondents (more than 60%) identified as White (White British, White Irish or White from other backgrounds). 9% identified as Asian or Asian British and there were no responses from Black or Black British ethnic groups.
- Religion: a majority of 48% reported No Religion, with 22% reporting as Christian.
- Sexual Orientation: a majority reported as Heterosexual/Straight (43%)

For more detailed information about the demographics of respondents– see the full survey results in [Appendix 4](#).

### Professionals' views

The professionals' autism needs assessment survey ran from 27/01/22 until 18/02/22 and received a total of 43 responses, with 95% reporting as working with autistic people and 5% being both an autistic person and a professional working with autistic people.

The survey sought to get the views and experiences of professionals working or supporting autistic people focusing on Diagnosis and assessment; General health; Local health services; Training for professionals; Local services (other than health).

The survey also gathered demographics data about age, gender, ethnicity, religious beliefs and sexual orientation.

### Diagnosis and assessment

#### Main themes

- **Long waiting times and waiting lists for assessments and special school places**
- **No communication from CAMHs**
- **Complex additional conditions and co-morbidities**
- **Support in schools not adequate and specifically autism orientated, including limited access to support from Occupational Therapist (OT)/Speech and language therapist**
- **Free training as an incentive for schools to upskill on best practice**
- **More collaboration needed between CAMHs, Schools and Families**
- **Resources and support needed for complex conditions**

The majority of respondents (83%) work with people or groups of people who had a formal diagnosis of autism.

The main conditions associated with the person(s) they work are:

1.	Sensory processing difficulties	51%
2.	Learning disabilities	44%
2.	Attention Deficit Hyperactive Disorder (ADHD)	44%
3.	Epilepsy	26%
4.	Dyspraxia	23%
5.	Visual or hearing impairment	21%

Other reported conditions were

- Obsessive Compulsive Disorder (OCD) (19%)
- Tourette's Syndrome (14%)

- Dealing with Trauma
- Global development delay
- Cerebral Palsy
- Chromosomal Disorder
- De novo chromosome 17q22 deletion
- Scoliosis
- Generalised hypotonia
- Restrictive Food Intake Disorder
- Oppositional Defiance Disorder
- Pathological Demand Avoidance

The age bracket at which most were diagnosed is 7-11 (21%) followed closely by 0-4 and 5-7 age brackets (16% respectively). However, it needs to be acknowledged that the way the question was framed didn't allow for other scenarios such as for professionals who "work with CYP 0-25y and diagnosis can be received at any time". Thus, the response rate of Unknown at 28% is significant in this context.

When asked about the waiting time for an assessment, 53% stated that the waiting time was more than 18 months, with 33% indicating that it was not a smooth process and that the autistic person didn't get any information. On a positive note, a substantial number of respondents reported that there was clear information about the diagnosis process whilst waiting for an assessment (16%), that other support was on offer (19%) and the autistic person were kept informed about waiting times (12%).

21 respondents gave additional information about the assessment process.

It was acknowledged that "once parents are in agreement for referral the process can be lengthy", but schools can't always prioritise use of the 'Educational Psychologist' time to support.

There is not "anyone employed to offer specific autism advice and support schools" and "Occupational Therapist (OT) and speech and language" support are limited.

The school environment is not "practically" conducive to "reducing sensory overwhelm" due to "space, funding and staffing". "Schools can feel abandoned" if they have a large number of autistic children to look after.

A more consistent approach to best practice in mainstream schools is needed, however concerns raised if schools need to pay for more training, "they may not opt in".

"Early identification and support of Education and Health Care Plan (EHCP) in place before entry to school would support children to thrive".

In addition, a holistic whole family assessment of needs is needed because "all families...have a different experience". Families who are aware of what support is available can choose to access it but "those who shout loudest receive support quicker".

The experience of each autistic child in a classroom is "unique".

Whilst waiting for the formal assessment, parents should be signposted to "Parenting Special Children" for interim support, advice and guidance. At the moment, parents are left waiting without support or information.

The above comments re-affirmed the findings on the question about the experience of the assessment process. 37% of respondents said that there wasn't enough information about the diagnosis or about support available, closely followed by 30% saying that the whole process was challenging and not clear. However, 14% found that there was good information about the diagnosis but not what support was available. A smaller proportion of respondents said that there was good information about the diagnosis and what support was available and that the assessment was adequate, both at 5% respectively.

20 respondents offered additional comments about their experience of the assessment process.

One respondent suggested that “it would help schools to get advice about reasonable adjustment and specific supports at the same time as parents because every autistic child is different”.

One family experienced additional stress due to language barriers and their child not being able to get the support they were told he needed due to long waiting lists for a place at a special school.

“Not everyone has a good full (assessment) report at the end...some parents feel scared and not sure where to turn to next”.

### *General health*

Main themes

- **Specialist support and pathways needed to address complex health concerns**

When asked about describing the general health of the autistic person they are supporting, a majority of 37% responded ‘Good’ followed next by ‘Just OK’ at 19%. Only 7% reported general health as ‘Very good’ with 7% as ‘Poor’ or ‘Very Poor’.

Professionals further commented that the main health concerns of those they support or work with gravitate around mental health, anxiety, loneliness or “feeling different, unlovable or not clever”, “self-harming” or “suicidal thoughts”. There a couple of comments about unique cases such as “PICA type behaviours” or “extreme social emotional and mental health needs (SEMH)” for which there is no “appropriate pathways to support” or “limited external CAMHS support”.

“Food challenges”, “limited eating”, “vitamin deficiency” are also a “huge concern with not enough understanding and resources to support autistic children & young people with regards to their restricted diets”.

Other areas of health concerns raised were “weight gain, teeth or general oral health” and “support to access the community dentistry or school nurses” was mentioned.

### *Local health services*

When asked how accessible local health services are for autistic people, professionals responded that local health services are not very accessible (37%), closely followed by those who thought that local health services are reasonably accessible with reasonable adjustments needed (35%). Interestingly, 21% of respondents said that they don’t know what local health services are available for autistic people.

### *Training for professionals*

Main themes

- **Awareness raising sessions to support autistic people**
  - **for: school staff, businesses, statutory professions**
  - **about:**
    - **What autism is and is not**
    - **How to meet the needs of autistic people**
    - **What local health services are available**
    - **What local (community) services are available**
- **Build upon existing training resources such as Autism Education Trust (AET)**
- **Need to increase capacity in mainstream schools for more autism trained specialist staff**

We asked professionals if they had received sufficient support and training to help them support autistic people in their role. The majority responded affirmatively (70%), however a substantial 28% said they hadn't.

Additional comments on the topic of training cited the following suggestions:

- "it would be useful to have more training on support in mainstream curriculum design for non-verbal autistic people with signs of cognitive delay or impairment"
- "be able to hear the voices of autistic children using video – this is powerful to use with schools"
- "improve capacity to support through the Autism Education Trust (AET) hub and also consider how we can enable "advisors" to be available to do sustained systemic work with school leaders rather than fire-fighting and crisis management"
- "Further support and training of where to go for support, process of diagnosis, how to support the family", "children with autism, particularly those with poor communication skills"
- "Training in supporting their mental health and knowing what is available in the way of help for them (both in mental health and generally) would be useful"

Issues around collaboration of services and capacity for responding to needs were raised:

- "school are experiencing direct consequence of high levels of need"
- "capacity in school is finite means often training is inappropriate to professionals"

Overall, more training or awareness raising/refresher courses would be welcomed, with an acknowledgement that hands on experience and learning to see each child as "individuals and not a series of conditions on a page" are valuable.

#### *Local services (other than health)*

Main themes

- **A variety of services are available but more local knowledge and insights needed about what is available**
- **Need to invest into activities and services adapted or adjusted to meet the needs of autistic people**
- **Awareness raising sessions to professionals in variety of sectors (businesses/transport/employers) about what autism is and what is it not and on how to meet the needs of autistic people**

When asked about what they thought of the availability of local services for autistic people, 49% responded that there is only a limited range of services in this area that consider the needs of autistic people and a lot of improvement is needed. In addition, 46% said that they thought the local services on offer for autistic people in the area were reasonable with room for improvement. Only 2% thought that there is a good range of services that consider the needs of autistic people in the area.

When asked what local services are accessed and what changes would make it easier to use local services more, professionals commented that as follows:

#### *Local services accessed*

- Outside Reading – Camp Mohawk in East Berkshire
- "supermarkets, parks, children's indoor play areas such as Red Kangaroo and soft play facilities"
- Thames Valley Adventure Playground
- "Most places are generally accessible if the person is wearing a SEN lanyard"
- "Cafes, shops, Swimming, Gym, cinema"

- “Parenting special children, ASSIT, Autism Berkshire”
- “some good holiday clubs available for certain ages and ability”
- “Autism Education Trust (AET) ... are training schools to become more aware of autism”

#### *Changes/Suggested improvement*

- Adapt holiday clubs to suit the needs of the autistic person
- More funding needed for Autism Advisory service for Children & families. Currently only 1 person in post “across Reading”
- “More social opportunities”
- “More SEN purpose-built play areas (i.e., with secure, tall fencing, natural sensory areas and sensory gardens, clear signage with symbols such as those made with InPrint”
- More awareness raising and training for “more understanding from professionals such as, for example, bus drivers, the police, staff at railway stations and shop staff”, “hairdressers, supermarkets” staff
- “cafes and shops” staff “need to clearly indicate to their customers that they can support people who are neuro-diverse and how the customer should let their staff know that support/adjustments are required”
- “More Social enterprise projects such as setting up a I run by lived experienced local people”

#### *Experiences or suggested improvements in support provided*

#### Main themes

- **Better communication between statutory services, schools and parents**
- **Schools to have the appropriate funding and support to help autistic children and their families**
- **Facilitate Respite for families**
- **Develop access to out of school provision and activities**

Finally, we asked professionals to tell us anything else they would like to share about their experience and any suggested improvements in support provided.

A total of 27 respondents contributed their views and suggestions

- CAMHS could “issue a letter saying [to parents they] are on the list at present there are 40 people in front of you rough time is 18months etc. If a parent, or school, does not return all the paperwork or it is lost a person can come off the list with no one knowing – again a confirmation letter would help. It would be useful for school to be copied in where possible, perhaps ask for consent early on to keep schools informed and then copies of the letters could go to them – particularly if meetings have not been followed up”
- “more help and support for parents”
- “supporting schools more to enable them to make the changes and adjustments that make most difference”
- Specialist setting funding and training are needed for children who are “waiting for a special school place” while in mainstream school with “a specialist teacher” who can provide “specialist support”
- The voice of some parents who are not able to be “strong advocates for their children” “may get overlooked and not heard”
- Facilitate access to Respite for families
- Access to mental health services for autistic people need to be improved
- Need “services in place to support people waiting for a diagnosis who still need support but haven’t been given the paperwork required to get it”
- Develop provision of “general weekend clubs where parents can drop off and collect later ...especially for students with complex autism” and “over the school holidays”

- Accessibility of information need to be looked into: “information about services needs to be visual and easy for parents to digest and understand”
- “psychologists or GPs” could be invited to spend time in unit schools or units dealing with autism “to have hands on experience of working day to day with autistic children”
- Need more “local disability confident employers”

### *Demographics*

- Gender: a majority of female (91%) responded. Males respondents represented 2% and 7% preferred not to say.
- Age group: the majority of respondents were in the 25-34 and 45-54 age brackets, respectively at 33% and 40%, followed by 35-44 at 16% and 55-64 at 9%.
- Ethnicity: the majority of respondents (more than 70%) identified as White (White British, White Irish or White from other backgrounds). There were 2 respondents from a Mixed ethnicity (4%) with one identifying as Asian or Asian British – Indian (2%) and one as from Black or Black British ethnic group (2%).
- Religion: a majority of 40% reported No Religion, with 33% reporting as Christian.
- Sexual Orientation: a majority reported as Heterosexual/Straight (74%)

For more detailed information about the demographics of respondents see the full survey results in [Appendix 5](#).

### *Parents/carers views*

The parents and carers autism needs assessment survey ran from 27/01/22 until 18/02/22 and received a total of 88 responses.

- The majority (87.5%) of respondents were carers, parents or a family carer supporting an autistic person, with 9.09% an autistic carer, parent or family carer supporting an autistic person.
- The majority of the respondents to the survey were female at – 82.95%; 10.23% were male.
- The largest age group responding to the survey was ages 35-44 at 38.64%, followed by 45-54 at 31.82%. No responses were received for the age groups 18-24, or 75 plus.
- White British was the largest ethnic group that responded to the survey, at 67.05% of all responses. This was followed by the Asian or Asian British Indian ethnic group at 6.82%.

### *Diagnosis and additional conditions*

#### Main themes

- **Long waiting time to get an assessment**
- **Assessment process is difficult and challenging**
- **Process reported to be easier if the child is already in contact with health services**

Of those who responded to the survey, 85.23% of parents of respondents or those who are being cared for by respondents had received a formal diagnosis of autism. In terms of additional conditions, sensory processing difficulties accounted for the largest percentage at 46.59%, followed by attention deficit hyperactive disorder at 34.09%. Other conditions included anxiety and mental health difficulties and dyslexia.

Respondents were asked the age of their child or person they cared for when they were diagnosed with autism. The majority were aged between 0 and 11 years old at 85.23%. None of the respondents answered with over the age of 19.

Respondents were also asked if the person they support has a diagnosis, was the process easy. 50% of all responses selected the option that no, it was not easy to request the assessment process and get diagnosed. 39.77% responded that yes, it was easy to request the assessment process and get diagnosed. There were a total of 56 responses telling us about the parent or carer's experience of getting a diagnosis for their child or person they cared for. Themes included the a very long waiting list for being assessed and receiving a diagnosis with some parent carers going privately, and the process being difficult and challenging. This is demonstrated by quotes taken from the survey below:

'The process is ridiculously long and drawn out, extremely hard to get professional support to get a diagnosis.'

'It was a very long process and stressful. Which included a lot of chasing professionals for reports and a long wait for assessment.'

There were however also positive experiences where the child had already been in contact with health services:

'With the amazing work at RBH after his first diagnosis of cerebral palsy and regular appointments for therapy and consultations picking up on the autism and getting a diagnosis was an easy process'

'The request was smooth. The Speaking & Listening assessment after child turning 2 years was done and ASD observed. The referral was quick and smooth'

#### *Assessment*

##### Main themes

- **Over half of the respondents waited for over 18 months for an assessment**
- **Lack of communication and updates on position within waiting list from CAHMS**
- **Limited information before assessment appointments**

Respondents were asked about their experience of waiting for an assessment. The waiting time was more than 18 months was the most chosen answer, at 51.14% of all responses, followed by it was not a smooth process and I didn't get any information at 35.23%. The least selected answer at 5.68% of respondents was – I was kept informed about waiting times.

The response to the above question are put into context by the responses to the follow up question asking respondents to give details. A lack of communication and updates from CAHMS was a common theme, alongside a lack of support. Below are quotes taken from the survey demonstrating this:

'We were given no additional information or kept up to date. In the end, we resorted to calling CAMHS every month to check that we were still on the waiting list.'

'No information. No help. Nothing.' 'Would be good if the concerned department send update with progress of waiting times. Also no call phone returns or email response'

Respondents were also asked 'what was there experience of the assessment?'. The most selected answer was 'there was good information about the diagnosis and what support was available' at 25%. However 12.5% said that the 'whole process was challenging and not clear'. Responses to the free text element of this question were also varied, with some parent carers citing the assessment as a positive experience, but others criticising a lack of support and guidance, and information before the appointment. A lack of post-diagnosis help and support also extended to assessments that had been undertaken privately.



### *Post-diagnosis support*

#### Main Themes:

- **Positive acknowledgements of support from VCS organisations**
- **Lack of post-diagnosis support and information from CAHMS**

The majority of responses to the 'what was your experience of post-diagnosis support?' portrayed a negative experience. 32.79% of parent carers responded to the question with they received no support post-diagnosis, a further 20.45% said that the support could have been better, and 17.05% said that the support was not adequate. It must also be noted that 13.65% of respondents said that they had a lot of support. Only one respondent to the questionnaire had been offered support but had declined it.

This was reflected in the free text element of the question, with many of the responses stating they were on their own post diagnosis from a CAHMS perspective, for example 'I received no support and no understanding of what to do with my son' and 'We've had none. I got a letter saying diagnosis was acknowledged and best of luck for the future.'

However, there were also positive acknowledgements of the support delivered by Autism Berkshire and the Autism Advisor.

Recommendation/Gap – Increase awareness and information in the CAHMs service of local post-diagnosis support and provide 'support regarding education and available local resources'.

### *Health*

- **A range of additional health issues were cited by respondents, particularly sensory difficulties impacting diet, low physical activity and mental health**
- **Reasonable adjustments for autism are not common place for healthcare services, and often need to be requested**

Respondents were asked to describe the general health of their child or person they cared for. The majority said that their health was very good or good at 68.18%, with only 5.69% poor or very poor. Of those that answered poor or very poor, a free text option was available. Dietary problems, including limited diets due to sensory processing difficulties were cited, alongside a lack of exercise and poor sleep. Poor mental health and suicidality was also cited by one respondent.

Respondents were also asked how accessible local health services are for autistic people. 42.05% said that health services were reasonably accessible, but reasonable adjustments need to be requested. 30.68% said that they were not very accessible, and 21.59% didn't know. The least selected answer at 3.41% was very accessible, and reasonable adjustments are offered.

Recommendation/gap – Information and guidance for healthcare services, for example the GP toolkit to be communicated.

### *Housing*

#### Main themes

- **Housing needs being met is not uniform across the housing system, with some parent/carers having positive experiences, some being unable to access support**

The majority of respondents stated that the person they care for or child/adult child lived with family, at 35.23%. This was followed by 34.09% owning their home. No respondents stated that the person they cared for or adult child lived alone without support or lived in supported housing, a care home or shared lives home. 14.77% rented home from the council, and 15.91% from a private landlord.

Most respondents responded to the question – Did they get any help to find a safe and comfortable home with not applicable at 56.82%. A further 27.27% stated that they did not get help, and 6.82% that they did. The free text below this question asking respondents to tell us what help this was, what worked well and what didn't work so well received 12 responses. Experiences varied, with some parents and carers describing a positive experience accessing housing:

'Has his own room as entitled. Contains all of his sensory needs. We receive UC.'

However, others described the difficulties faced whilst trying to access accommodation or adjustments for additional needs:

'We asked for accommodation but didn't get any help.'

'When my last tenancy ended I sought housing help and I had no choice but to go into renting an expensive property that I struggle to afford as a part time working single parent family with special needs.'

### *Schools and Education*

#### **Main themes:**

- **Getting support from school for most respondents is very challenging**
- **Positive feedback from some parent/carers around specialist schools or schools with additional needs units**

Amongst respondents the type of schooling reported ranged between attendance at a specialist school or unit (37.5%), mainstream school with additional support (31.82%) and mainstream school without additional support (26.14%). 1 respondent reported home schooling, and 1 reported private school with additional support. Almost 40% of respondents answered the following question around experience of school life with 'they didn't receive the support they needed throughout their schooling. 34% reported that they did receive the support they needed. The majority of respondents reported that their experience of schooling and getting support for their child or person they care for as very challenging, reporting that 'school has been a catastrophe' and 'truly awful, especially secondary'. There was however some positive feedback from parent/carers with some reporting that they had met their child or person they cared for needs, particularly around specialist schools or schools with additional needs units. For example, a parent commented that 'maximum support and guidance was received from New Bridge Nursery (Snowflake). They had been outstanding'.

### *Employment Support*

- **This section did not apply to the majority of respondents to the questionnaire**

Most respondents answered the question – did they get help to chose what to do after completing school with not applicable at 64.77%. Of those that were applicable, 11.36% responded that there was no support available with training, further education or work choices, and 6.82% replied yes, support was available. Comments within the free text below mentioned how advice seemed to be centred on university admissions, and how transitions into adulthood are vague in terms of information. The following question asking – how did they find the support offered, 62.5% again said that it was not applicable. 10.23% said that it was good and comprehensive, and 12.5% poor and difficult to access.

### *Transport*

- **Training for transport staff, and better awareness of autism is key to improving services**
- **Free bus passes, and the Readibus service reported as positive**
- **Some respondents felt the transport was not appropriate for their child or needs of person they cared, particularly with school transport.**

Respondents were asked what their experience they had of transport options available to the autistic person they are caring for. Almost 32% of respondents reported that it is stressful and/or causes anxiety, there is no information or support. 17.05% reported that staff were helpful and there is support and information available, and 11.26% need additional help with transport. There were mixed responses within the free text section, with some respondents reporting that school transport was 'extremely challenging' to access, being fearful of transport – 'he is too scared to go on public transport for fear of being beaten up'. However, others reflected on the benefits of a free bus pass, and services such as Readibus working well. In order to improve transport services, respondents reported that education for bus and taxi drivers was key to improving transport experiences – 'Better awareness of Autism and training the staff on how to help/support' and having continuity of bus drivers and taxi drivers – 'Consistent drivers who show up on time, every time. Drivers who know the needs of the child and are trained in how to communicate with them'.

### *Local Services*

- **The majority of respondents felt that there is only a limited range of services that consider the needs of autistic people**
- **Difficulties reported on environments not being autism friendly, and difficulties finding social clubs**
- **Positive feedback received for local services provided by the VCS**

The majority of respondents (63.64%) reported that there is only a limited range of services in this area that consider the needs of autistic people, and a lot of improvement is needed. 6.82% reported that there was a good range of local services. 54 respondents entered into the freetext box asking what services they accessed and what would make it easier for them to use local service more. Respondents talked about a range of services that they had accessed including those provided by Autism Berkshire, Autangel and Berkshire Autistic Society. However, others reported difficulties with environments such as shops not being autism friendly, and difficulty finding friendship clubs – 'There should be more group/ social activities as most of them needs contact with peers' and accessing one to one support that may be needed to access local clubs. A parent commented that they have been 'liaising with local amusement centre to have dedicated time slot for kids with special needs and at concessional prices'.

### *Family and carer support*

#### Main themes

- **Less than 10% of respondents felt supported by statutory health and care services and voluntary sector and community sector services in their caring role**
- **Facilitate access to breaks for families and carers**
- **For primary school age children, better child-care provision and activities during half-term and school holidays or weekend clubs are needed**
- **Improve communication to keep parents informed of progress or additional services available**
- **Fund 'more staff who assess children for autism'**
- **'Trauma support for siblings and family dynamics observations to ease the parenting task'**
- **Universal support needed for all carers of autistic people**

Parents and carers were asked how they felt they were treated by others and what support they received. A majority of 39% reported that they felt supported by family and friends in their caring role, with 31% reporting that health and care professionals include them in discussions and respect their expertise.

Some parents and carers are able to access training which helps them in their caring role (23%) with a few finding it easy to access information and advice which helps them in their caring role (11%).

However, 8% felt that they were supported to take care of their own health and wellbeing and 7% reported that they are able to take regular breaks from their caring role. A similarly low percentage (8%) reported that they felt supported in their caring role by voluntary sector and community sector services. Only 5% reported that they felt supported in their caring role by statutory health and care services.

In addition, 50 respondents gave their experience and gave suggestions to improve the support provided.

'Access to special needs school can be improved' and need to 'Restart some of the activities (e.g. trampoline, etc.) that used to happen before Covid 19 so that parents get a chance to meet similar carers/parents and can seek/get support/help'.

Communication and being kept informed are essential aspects raised by parents and carers, 'parents are not always included or kept informed, especially when there are multiple agencies involved'. 'There needs to be much more coordinated approach to supporting families in how to access information about autism, where to turn to first'.

Additional support needed to 'get into suitable employment' and improve housing situation after children reach 16+.

Concerns were raised about waiting times and distressing situations whilst awaiting for an appointment 'have more staff who assess children for autism. CAMHS takes ages for appointments, by the time we get appointment parents and children suffer a lot'

'I need universally accessible public services (starting with a suitable education for my child), and professionals who discharge their statutory duties according to the law.'

A parent commented that 'it would be valuable to have a way to connect with other parents/carers with children of a similar age' as well as 'Trauma support for siblings and family dynamics observations to ease the parenting task'.

Some parents and carers 'without friend and/or family to help "do not feel supported in their caring role"'.

Concerns raised about not being able to get a carer's assessment from the commissioned provider with the result 'I have given up even trying to get an assessment now'

Planning for the protection of the autistic person who need additional support to live independently was raised as a concern 'We are very concerned about what happens to her if something happened to us, her parents'.

'There needs to be more activities for higher functioning autistic adults. At the moment all the activities are focused on those with learning disability and not autism specific'

Carers of autistic adults 'feel there is more support for carers with young children but the carers of adults are often less supported'.

## 7.2.7 Unmet needs and gaps – stakeholder engagement

Table 18. Feedback summary – unmet needs and gaps

Theme	Feedback/Unmet needs and gaps
<b>Pre/Post diagnosis support</b>	<ul style="list-style-type: none"> <li>• Reduce waiting times</li> <li>• Provide interim support and clear information about what services are available</li> <li>• Support and awareness amongst parents are not uniform or equitable</li> <li>• Whole family assessment of needs to address specific concerns at home, at school, in the workplace</li> <li>• More collaboration between CAHMS, schools and families</li> <li>• Improved communication with CAHMS, including updates on position within the waiting list and pre assessment information</li> <li>• Publicise PSC/Autism Berkshire service even more and information on BHFT website – this is in the new SEND guide for parents.</li> <li>• Ensure schools are reminded of the support available to share with parents</li> <li>• A leaflet for those on the waiting list for assessment would be helpful explaining where to get support, including social care, Engine Shed and the PSC/Autism Berkshire work.</li> </ul>
<b>Transport</b>	<ul style="list-style-type: none"> <li>• More awareness training of bus drivers and transport staff about how to meet the needs of autistic people</li> <li>• “autistic people need access to bus passes with extra support needs printed on it, even if it has to be paid for – preloaded with ‘x’ amount of trips”</li> <li>• “temporary blue badge scheme”</li> <li>• School transport is not always appropriate for autistic children</li> </ul>
<b>Housing</b>	<ul style="list-style-type: none"> <li>• Consideration of the autistic child’s needs to occur when providing and assessing for housing</li> <li>• Consideration of the surrounding of environment when housing autistic people, including being close to transport routes, local amenities and support network</li> <li>• Develop clear strategy for providing supported accommodation for autistic adults to ensure that are safe and reliable options for autistic adults that ensure their health.</li> <li>• Ensure this information is communicated to young people and families</li> </ul>
<b>Local health services</b>	<ul style="list-style-type: none"> <li>• Accessing and getting reasonable adjustments, particularly at the GP Surgery. Suggestions include Increased time in healthcare appointments to process information and ask questions, reduced reliance on phone calls</li> <li>• Annual health checks being should be made available for all autistic people</li> <li>• Better awareness of what autism is and the environmental/sensory impact on autistic people within healthcare settings</li> <li>• Mental health support is a priority</li> <li>• Specialist support and pathways needed to address complex health concerns</li> <li>• Training for hospital staff in responding to autistic adults and children</li> <li>• Develop support for children and young people who are fearful of medical procedures and needles.</li> <li>• Develop more support for autistic children and young people with restrictive diets incl. Avoidant/restrictive food intake disorder (ARFID)</li> </ul>
<b>Local (community) services</b>	<ul style="list-style-type: none"> <li>• Every day services may not be accessible to autistic people, adjustments may be needed, for example ‘autistic hours’ in supermarkets</li> <li>• More local knowledge and insights needed about what is available</li> <li>• Need to invest into activities/services adapted or adjusted to meet the needs of autistic people</li> <li>• More trained support workers to run activities in the community</li> <li>• Need to adjust environments where activities or services are delivered from to minimise sensory impact</li> </ul>

	<ul style="list-style-type: none"> <li>• Need a range of activities covering the full spectrum including for 'higher functioning autistic adults'<sup>96</sup></li> </ul>
<b>Education</b>	<ul style="list-style-type: none"> <li>• Behaviour within schools can be misunderstood, leading to unnecessary exclusions and potentially risk of entering the criminal justice system</li> <li>• Ongoing improved understanding and awareness of autism within the Education sector</li> <li>• Some schools support autistic children well, but this is not consistent across schools.</li> <li>• Insufficient support and signposting after completing school or to enter into employment</li> <li>• Bullying within schools is common and can result in autistic children missing school</li> </ul>
<b>Social Experience</b>	<ul style="list-style-type: none"> <li>• Bullying and exclusion from social events is common and a significant problem for autistic children</li> <li>• There needs to be more inclusion and training for sports clubs</li> <li>• There is a limited range of activities for autistic children, young people and adults</li> </ul>
<b>Employment</b>	<ul style="list-style-type: none"> <li>• Improved understanding and guidelines for employers around autism, including reasonable adjustments</li> <li>• Improved support and employment assistance for those over 25</li> <li>• Support for autistic young people to enter the workplace</li> </ul>
<b>Family &amp; Carer Support</b>	<ul style="list-style-type: none"> <li>• Increase capacity for support by statutory health and care services and voluntary sector and community sector services to parents and carers</li> <li>• Facilitate access to breaks for families and carers</li> <li>• Improve communication to keep parents informed of progress or other services available</li> <li>• For primary school age children, better child-care provision and activities during half-term and school holidays or weekend clubs are needed</li> <li>• Support to get into employment and find suitable housing</li> <li>• Funding for 'more staff who assess children for autism'</li> <li>• 'Trauma support for siblings and family dynamics observations to ease the parenting task'</li> <li>• Facilitate access to a carer's assessment</li> <li>• Family protection planning</li> <li>• Universal support needed for all carers of autistic people</li> </ul>
<b>Training</b>	<ul style="list-style-type: none"> <li>• Awareness raising sessions to support autistic people for: healthcare and education professionals, businesses, employers, statutory professions, about: <ul style="list-style-type: none"> <li>○ What autism is and is not</li> <li>○ How to meet the needs of autistic people</li> <li>○ what local health services are available</li> <li>○ what local (community) services are available</li> </ul> </li> <li>• Build upon existing training resources such as Autism Education Trust (AET)</li> <li>• Need to increase capacity in mainstream schools for more autism trained specialist staff</li> </ul>

## 8 | Unmet needs and gaps

A range of unmet needs and gaps have been highlighted throughout the report and recommendation to close these gets in a bit to work towards meeting these needs have been made below. Action in certain areas may already be underway but need to be taken forward, whilst others need to be initiated. Overall, a prioritisation process is required to ensure resources are directed towards the areas of greatest need, that will have the greatest impact in improving the overall health and wellbeing of autistic people in Reading, including their families, carers and those that support them.

<sup>96</sup> **A keynote of terminology/language used.** The report is structured as is typical for a Needs Assessment in Public Health. It is acknowledged that different people have different views on terminology relating to autism. In this instance, we have kept the term as per the feedback received for transparency and accuracy.

## 9 | Conclusions

Some areas have not been addressed in this Needs Assessment in detail or at all as they were beyond its scope. These include the implications for service provision of the more aging autistic population, stop and search practices related to autistic people, in particular those of Black African/Caribbean ethnicity, autistic young people’s complex educational needs in particular those beyond statutory school age, some of the social implications of autism including societal participation. The multi-agency Autism Board in Reading must be supported to ensure that key work and insights contribute to timely, appropriate provision of services and resource for Readings population of autistic people and those that support them. Readings Autism Board will be developing it’s All Age Autism Strategy informed by the findings of the All Age Needs Assessment.

## 10 | Recommendations and next steps

*Table 19. Call to action (Recommendations for commissioning)*

<ul style="list-style-type: none"> <li>Whole system approach to autism engaging the full range of stakeholders across the system.</li> </ul>	<i>RBC, Local authority commissioners</i>
<ul style="list-style-type: none"> <li>Evaluate marketing and promotion of services and support available to autistic people</li> </ul>	<i>Public Health, Local authority commissioners</i>
<ul style="list-style-type: none"> <li>Improve capacity and quality of support for education, physical and mental health and social care to ensure timely, accessible support and reduce reliance on a crisis response for autistic people and, especially, children with complex needs</li> </ul>	<i>BFFC, Commissioners, Service providers</i>
<p><b>Diagnosis</b></p> <ul style="list-style-type: none"> <li><b>Continue with the work on changing the culture across the system</b> Working across system to achieve a culture shift moving towards needs led rather than diagnosis dependent support and with a recognition of neurodiversity (difference rather than deficit) <ul style="list-style-type: none"> <li>Accessing help based on need, as early as possible / Promoting acceptance of neurodiversity</li> <li>Strength based approach / Shared language</li> </ul> </li> <li>Additional rollout and promotion of autism training for relevant front-line health and care staff for early identification, support conversations with individuals about autism and signpost to appropriate support services. Includes strengthening opportunities to develop and reinforce knowledge and skills of staff working across a range of roles in the community.</li> <li>Reduce waiting times, and link people into appropriate support more quickly following assessment and diagnosis e.g., recruitment of additional Autism Advisors</li> <li>Develop a communication protocol between professionals and suspected autistic people and their families throughout the pre and post diagnostic journey.</li> <li>Level of support for autistic people and their families to be proportionate to the demand for services. Ensure resources within assessment settings can meet the demand for assessment.</li> <li>Consider dedicated autism support within educational settings pre and post diagnosis to facilitate in narrowing the gap and increasing support networks.</li> </ul>	<i>Public Health, Local authority and CCG commissioners, Service providers, BHFT, BFFC</i>
<ul style="list-style-type: none"> <li>Use multiple information sharing methods of raising awareness of existing pre and post diagnostic support provision and making it clear and easy to find, to aid proactive identification of people awaiting diagnosis, crisis prevention and avoidable admissions into inpatient mental health settings, making it easier to find and engage with the appropriate support throughout the life course.</li> <li>An early identification pilot involving healthcare and education staff working together to assess suspected autistic children in schools.</li> <li>Ongoing support of health, care and education staff skills to help in make appropriate adjustments and programmes developed to improve the health of autistic people and address inequalities faced by autistic people e.g., through Autism Health Checks.</li> <li>Oliver McGowan Mandatory Training on learning disabilities and autism for all health and care staff.</li> <li>Improve commissioners’ and social workers’ understanding and capability to develop the appropriate services and support provision required by autistic people.</li> <li>Prioritisation of autism by leadership in local health systems and recognition of commitments set out in the NHS Long-term Plan, the Mental Health and Wellbeing Recovery Action Plan and aligned with other priorities within the Berkshire West Joint Health and Wellbeing Strategy.</li> </ul>	<i>RBC, BHFT, Providers, BOB ICP</i>

<ul style="list-style-type: none"> <li>• Inclusion of Autism and Learning Disability Champions in the Integrated Care Partnership to implement accessible and quality autism and learning disability services.</li> <li>• All Integrated Care Boards, to focus on autism and learning disabilities at the highest level and have a named executive lead for autism and learning disability as recommended nationally.</li> </ul>	
<b>Social care, Children</b> <ul style="list-style-type: none"> <li>• Ensure autistic children, including those who are marginalised or from seldom heard groups, who are eligible for children's social care are actively supported to access the help they need.</li> <li>• Investigate increase in abuse/neglect as primary social care need in children.</li> </ul>	<i>Children's Social Care</i>
<b>Education</b> <ul style="list-style-type: none"> <li>• Monitor and evaluate AET training in mainstream schools</li> <li>• <b>Culture change in schools:</b> in addition to awareness raising, measures needed, include zero tolerance policies for bullying, autistic champions, and regular whole school and class discussions.</li> <li>• Review exclusions of autistic children to reassure local stakeholders that school environments are appropriate for autistic children.</li> <li>• Use the New minimum standards for preparing for adulthood funded by the Department for Education as a framework to build on the initiatives outlined in the recent Ofsted and CQC assessment</li> </ul>	<i>BfC</i>
<b>Adult Social Care</b> <ul style="list-style-type: none"> <li>• Mandatory and more detailed recording e.g., whether autism is a primary reason for using the system would aid confidence in the quality of the limited data available.</li> <li>• Autistic people who are eligible for adult social care support and use direct payments should be supported to find appropriate and suitably qualified personal assistants able to meet their needs.</li> </ul>	<i>Adult Social Care, Autism Board</i>
<b>Training and Employment</b> <ul style="list-style-type: none"> <li>• Sufficient representation on the Autism Board to include providers of training and education, e.g., JobCentre+, Elevate &amp; Reading College.</li> <li>• Employers to understand and accept autism, simplify the recruitment process and make reasonable adjustments to support accessibility for people with special needs as is also done and required by law for people with a disability.</li> <li>• Increase autistic people's confidence to make first contact</li> <li>• Increase opportunities to access employment</li> <li>• Job interviews - effective presentation – preparing for interviews</li> <li>• Liaise with employer to better coordinate the Job application process</li> </ul>	<i>Training provider, Service providers, BfC</i>
<b>Housing</b> <ul style="list-style-type: none"> <li>• Enable autistic people to live in housing appropriate to their needs and support those who want to or have to live independently.</li> <li>• Work collaboratively with local service providers to develop and improve data collection to promote consistent recording and analysis of the number of autistic people, their housing needs and consider autistic people's needs in local housing plans.</li> <li>• Data collection about housing needs should include projections of older adults and younger adults likely to have specific accommodation needs.</li> <li>• Autism training for housing staff and care providers to enable autism accessible housing processes, including promoting awareness and use of the Autism Toolkit. Joined up working with housing teams, development of a clear offer and autism housing pathway in partnership with RBC Adult Social Care and local homelessness organisations to ensure needs are met and continuity of service is provided.</li> <li>• Work with local emergency accommodation providers to improve understanding of autism.</li> </ul>	<i>RBC Housing Teams, Public Health, ASC</i>
<b>Parents/carers</b> <ul style="list-style-type: none"> <li>• Ongoing support for parents and carers at the outset even when a formal diagnosis hasn't been made.</li> <li>• A systematic whole family assessment to be done once an informal diagnosis is implied to identify and address the needs of the carer and the autistic person.</li> <li>• Ongoing structured and clear pathways support from school systems.</li> <li>• Review provision and commissioning of overnight respite to ensure it meets need and identify resources to increase provision and facilitate respite for autistic people and families.</li> <li>• Increase accessibility and support to resources for families and carers who don't have internet access, don't feel confident coming forward to ask for information, or for whom English is not their first language.</li> </ul>	<i>Service providers, RBC ASC Team, Autism Board, CCG</i>
<b>Transport</b> <ul style="list-style-type: none"> <li>• Expand autism training and how to meet needs of autistic people.to front line transport staff</li> <li>• Consistency of transport escort staff or advance preparation with autistic child/young adult in mind, to anticipate and manage change.</li> </ul>	<i>RBC Transport Teams, Schools, BfC</i>



<p><b>Criminal Justice System</b></p> <ul style="list-style-type: none"> <li>Autism Board to include a representative from Liaison &amp; Diversion Service.</li> <li>Service providers to work with Thames Valley Police to better document hate crimes and offer autism awareness training in order to better understand and support autistic people</li> <li>Strengthen Reading's partnerships across the CJS and between agencies locally so that autism needs are recognised and met.</li> <li>Early identification and support to prevent inappropriate involvement entry into the CJS, to prevent offending and support rehabilitation.</li> <li>Support autistic people with paid employment and fixed activity routines, that they feel safe and confident doing, minimising risk of vulnerabilities being exploited.</li> <li>Ongoing awareness raising of the Berkshire Autism Alert Cards to the CSJ</li> <li>Implement adjustments throughout the CJS to create autism friendly communications and environments.</li> <li>Develop and improve systems that can record reliable data on autism and allow systems to cross share information to help provide a complete picture of needs.</li> <li>Identify and deliver further specialist training packages for frontline CJS staff to remove barriers and increase awareness, understanding and acceptance of autism.</li> <li>Universal use of a consistent screening tool within the CJS is needed along with an information sharing protocol for information sharing between services.</li> <li>A clear social care pathway within the prisons in Reading and open social care referral process, which includes self-referrals from prisoners.</li> <li>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 individuals needs.</li> </ul>	<p><i>CJS, Commissioners, Autism Board, Training Providers</i></p>
<ul style="list-style-type: none"> <li>A commissioning model that better integrates services and budgets across organisations within the system. The capacity for a wider range of organisations to contribute to supporting autistic individuals and their families, needs to be assessed and mobilised.</li> </ul>	<p><i>Public Health Commissioners, CCG, ICPs</i></p>
<ul style="list-style-type: none"> <li><b>Improved data sharing and quality:</b> the whole system to share data on autistic individuals and enable more robust measurement of outcomes and better inform commissioning.</li> </ul>	<p><i>All commissioners, Service providers</i></p>

## 11 | Appendices

### Appendix 1 - Autistic People Needs Assessment Survey 2022



Autistic People -  
Autism Needs Assessr

### Appendix 2 - Parent and Carers - Needs Assessment Survey 2022



Parent and Carers -  
Needs Assessment Su

### Appendix 3. - Professionals - Autism Needs Assessment Survey 2022



Professionals -  
Autism Needs Assessr

### Appendix 4 - Autistic Adults NA report 21-02-2022



Autistic Adults Needs  
Assessment report 21

### Appendix 5 - Professional Needs Assessment Survey Results 21-02-2022



Professional Needs  
Assessment Survey re