Autism in Reading
Local Profile and Needs analysis

Brighter Futures for Children

NHS
Buckinghamshire, Oxfordshire and Berkshire West
Integrated Care Board

Reading Borough Council
Working better with you

Contents

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

1.0 Introduction

Autism is a national priority. This Local Profile is the result of contributions and input from a Steering Group made up of autistic people, carers, professionals working with autistic people, members of the Autism Board and multidisciplinary professionals from across Reading's system.

Those engaged throughout the development of this strategy:

- Autistic people, parents, carers
- Brighter Futures for Children
- Berkshire West Hub
- Reading Borough Council, Public Health Officers
- Reading Borough Council, Public Health Analyst
- Berkshire West Public Health
- Autism Berkshire / Parenting Special Children
- Reading Mencap
- Thames Valley Police
- Berkshire Health Foundation Trust (BHFT)
- Healthwatch Reading
- Reading Families Forum
- Talkback CAMEO
- Liaison and Diversion Service
- Probation Service
- Youth Offending Service

- The Department for Work and Pensions (DWP)
- Job Centre
- New Directions
- Other Employments related organisations
- Special United group
- Reading Autistic Families Together (RAFT)
- Compass Recovery College - Autistic adults
- Reading Families Forum - Attendees
- Autism Berkshire - Parents/Carers
- Engine Shed Session - Children/ Young people
- Parenting Special Children (Auticulate)

Our ambition is to have a whole systems approach to ensure Reading is a more inclusive place to live and that autistic people can get the right support they need when they need it.

2.0 Autism in Reading – Local Profile and Needs analysis

2.1 Local Numbers of Autistic People

Based on national estimates, there are approximately 1,707 autistic people in Reading, including 353 school aged children. The exact local number could be larger or smaller.

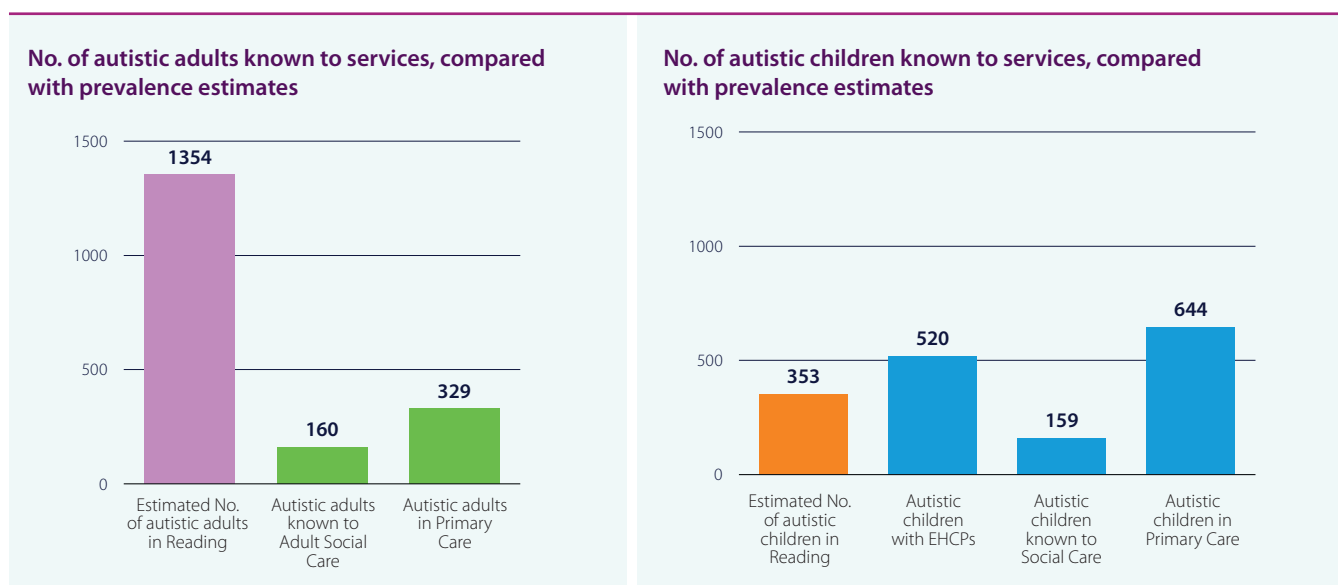### Table 1: Estimated number of autistic adults and children in Reading

Population Group	National Prevalence	Reading Population	Reading Estimated Number
Males 18+	2%	62,467	1,249
Females 18+	0.3%	60,616	182
Total 18+	**1.1%**	**123,083**	**1,354**
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	-
Total aged 5 - 19	**1.2%**	**29,441**	**353**

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

2.1.1 Estimated number known to services (children and adults)

Autistic people known to Reading services equated to approximately 489 adults (18+). 520 children had an EHCPs with autism noted as the primary need. 159 children aged 5-16+ years were known to children's social care in 2021 (children who met eligibility criteria for a social care service). 644 children had a diagnosis of autism recorded by their GP which suggests that more children in Reading are diagnosed with autism than average, but fewer adults.

Figure 1: Estimated number of autistic adults and children known to services

No. of autistic adults known to services, compared with prevalence estimates

No. of autistic children known to services, compared with prevalence estimates

2.1.2 Estimated number not known to services

Table 2: Estimated number of autistic adults in Reading by narrow age groups (using ONS population estimates 2020) compared to number of Reading residents diagnosed with autism recorded in primary care data (snapshot from March 2022)

Age Group	Estimated No.	No 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)

Assessment Referrals: On average approximately 1865 autism assessment referrals are made each year to Berkshire Healthcare NHS Foundation Trust for children, young people and adults [22]

2019/20
1775 people

2020/21
1955 people

2021/22 Quarter 1
755 people
In quarter 1, there were approximately 775 people in Reading, referred for an autism assessment and are awaiting a diagnosis.

Local data indicates that in Reading, generally referrals for autism assessments have been increasing from 2019/20 – 2021/22 and with each quarter.

Most new referrals into Berkshire Health NHS Foundation Trust 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. An improvement can be seen in 2020/21 with a larger proportion of referrals being seen within 13 weeks or less and between 13 weeks and 26 weeks, compared to 2019/20.

[22] 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].

Autistic children, young people, and adults in Social Care in Reading

Most common social care primary needs for autistic children between 2017 -2021

353 children with either an **EHCP** where autism identified as primary need known to children's social care or early help services (2017-21)

Annually, 150-200 known to children's social care (2017-21)

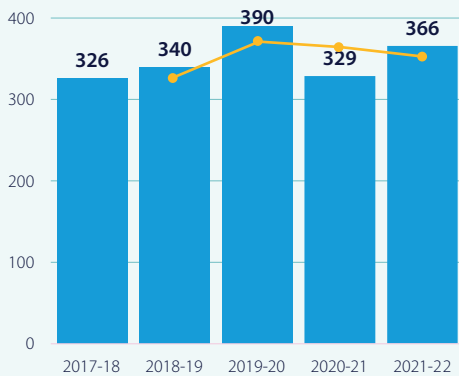Annually, 30-60 known to early help services (2017-21)
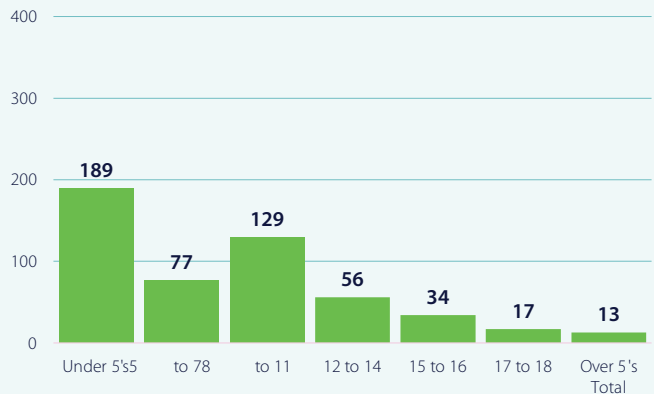
Disability 40%

Abuse or neglect 22%

Learning disability support 10%

Families in acute stress 14%

Figure 2: Children and young people referral, 5-year trend for autism, 2017/18 - 2021/22, Reading

Year	Value
2017-18	326
2018-19	340
2019-20	390
2020-21	329
2021-22	366

Figure 3: Children and young people currently waiting for autism assessment, Reading (as of March 2022)

Age group	Value
Under 5's5	189
to 78	77
to 11	129
12 to 14	56
15 to 16	34
17 to 18	17
Over 5's Total	13

Autistic Adults / People aged 18 and over in Reading

Adult Social Care (ASC)

- Considering the small numbers involved, there has been a relatively steady proportion of referrals, assessments and reviews yearly of autistic adults in ASC.
- 160 autistic people currently known to ASC in Reading. 75% are male and 24% are female.

Figure 6: Autistic people known to Adult Social Care, by Gender

Female

Male
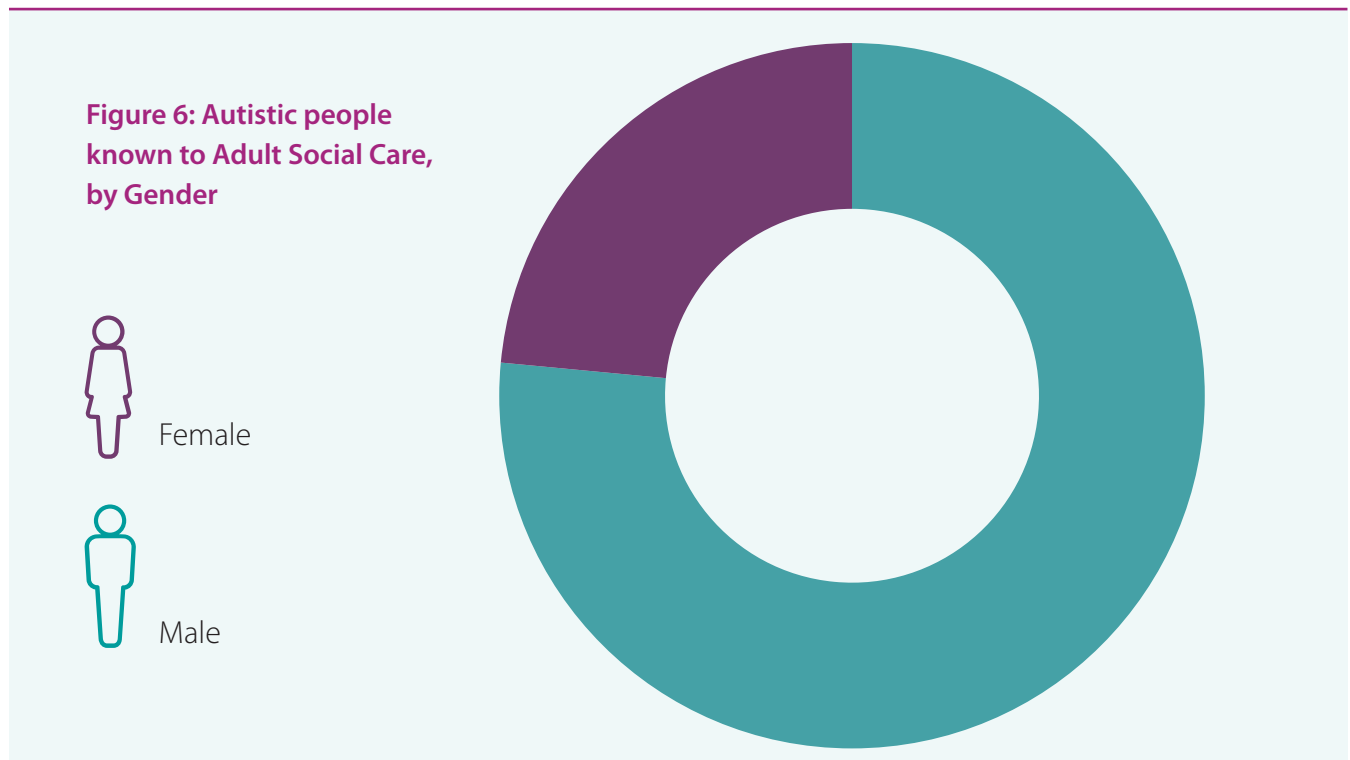
Lack of data in ASC is challenging and may relate to small numbers of autistic people using the system. Mandatory and more detailed recording such as whether autism is a primary reason for using the system would aid confidence in the quality of the limited data available.

2.1.3 Projections

Prevalence estimates and population projections suggest that the number of autistic people could increases to 383 (CYP – aged 5-19) and then decline up to 2040. They suggest a corresponding increase in 18-24 year olds from 2025 (205) and in 25-34 year olds from 2030 (257). The number of autistic people aged 65 and older is predicted to increase by 44% between 2020 (192) and 2040 (277).

Table 3.

People aged 18-64 predicted to have autistic spectrum disorders projected to 2024

Age Group	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 4.

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

Age Group	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

Table 5.

Number of children and young people predicted to have autistic spectrum disorders in Reading

| Age Group	2020	2025	2030	2035	2040
Children & young people aged 5 - 19	374	383	367	345	336

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

In 2022 it should be noted that the projected number of children and young people is less than the actual number of children with autism as a diagnosis on their primary care record and less than the actual number of EHCPs issued for autism as primary need.

Figure 4.

Reading residents predicted to have autistic spectrum disorders by age group projected to 2024
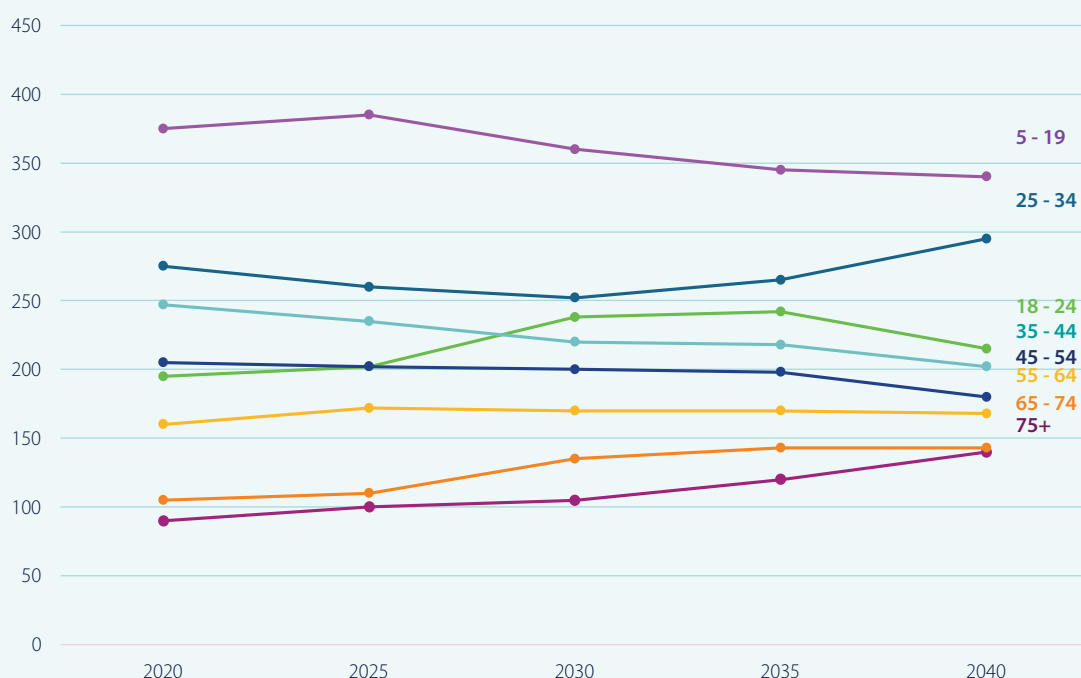
Predictions suggest the number of autistic children and young people will likely continue to increase until 2025 and then decline. They suggest a corresponding increase in 18–24-year-olds from 2025 and in 25-34 year olds from 2030. The number of autistic people aged 65 and older is predicted to increase by 44% between 2020 and 2040.