

East Berkshire Autism (autism) and Attention Deficit Disorder (ADHD) Analysis Project final report appendices



Improving health and wellbeing

Produced for East Berkshire CCG

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V1_0 DRAFT

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Appendix 1

Statistics headlines sources

Prevalence study - autism/ADHD - sources

	Description	Web link/Source	Prevalence
1	The number of children with autism known to schools in Bracknell Forest in 2017 is 258 which equates to 1.17% prevalence	http://health.bracknell-forest.gov.uk/jsna/developing-well/children-young-peoples-wellbeing/emotional-wellbeing-mental-health/	1.17% (aged 5-18)
2	During the 2014/2015 school year there were 316 children recorded as having a diagnosis of autism in Slough schools. This represents 1.08% of all pupils (similar to the national average).	https://www.slough.gov.uk/council/joint-strategic-needs-assessment/child-and-adolescent-mental-health.aspx	1.08% (aged 5-16)
3	The rate of school age children with autism known to their schools was 10.6 per 1000 pupils higher than the South East region where the average was 10.0 per 1000 pupils. (2013/2014 data)	https://www3.rbwm.gov.uk/publichealth/downloads/file/15/autism_in_children	1.06% (aged 5-16)
4	The actual number of children under 5 with autism in NHS Windsor, Ascot & Maidenhead in 2016: Aged under 5: 30 ; which translates to a 0.25% prevalence rate for under 5s.	Table 4 in RBWM 2017 Joint Autism Strategy	0.25% (aged under 5)
5	Estimate quoted a lot in literature and strategy papers is 1% prevalence for adults	Various sources incl JSNA's, POPPI & PANSI	1.00% (Adults)
6	The prevalence of Autism (including Asperger Syndrome) in school age children in Northern Ireland 2018, is 2.9%	https://www.health-ni.gov.uk/sites/default/files/publications/health/autism-children-ni-2018.pdf	2.90% (aged 5-16)
7	About 1 in 59 children (1.69%) has been identified with autism spectrum disorder (autism) according to estimates from CDC's autism and developmental disabilities monitoring (ADDM) network.	https://www.cdc.gov/ncbddd/autism/data.html	1.69% (Aged 5-16)
8	Studies in Asia, Europe, and North America have identified individuals with autism with an average prevalence of between 1% and 2%.	https://www.cdc.gov/ncbddd/autism/documents/autismPrevalenceDataTable2016.pdf	1% - 2% (various age bands)
9	A study in Canada (NASS) published a combined prevalence of 1 in 66 children and youth (i.e., 15.2 per 1,000) 5–17 years of age were diagnosed with autism - 1:66 (5-17 year olds) 1:63 (8 year olds)	https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-children-youth-canada-2018.html#a2-2	1.52% (aged 5-17)

Prevalence study – ADHD - Sources



	Description	Web link/Source	Prevalence
1	About 2 to 5% of school age children can suffer from ADHD. Boys are more commonly affected than girls.	https://www.rcpsych.ac.uk/mental-health/parents-and-young-people/information-for-parents-and-carers/attention-deficit-hyperactivity-disorder-and-hyperkinetic-disorder-information-for-parents-carers-and-anyone-working-with-young-people	2%-5% (Child)
2	Around 3-6 in every 100 school-aged children have ADHD. For about 1 in 7 children with ADHD, their ADHD will continue into adulthood. About half will have some problems as adults, although not full ADHD. In children, boys are more commonly diagnosed than girls, where as in adults, there are more equal numbers of men and women seen in clinics	https://www.rcpsych.ac.uk/mental-health/problems-disorders/adhd-in-adults	3%-6% (Child)
3	The prevalence rate for children with ADHD is between 5 to 7%, of whom approximately 65% will continue to experience symptoms in adulthood. In other words, roughly 3% to 4% of all adults have ADHD. To make it clearer, about 1 in 25 adults have ADHD. About a third of children are diagnosed, while for adults it is about 7-8% (Adhdaction, 2018)	https://aadduk.org/ http://www.adhdaction.org/	5%-7% (Child) 3%-4% (Adult)
4	According to one study 70% of children with autism will have at least one mental health problem with common diagnoses being social anxiety, ADHD , and oppositional defiant disorder	Simonoff, Pickles, Charman, Loucas, & Baird, 2008 (and various other sources)	
5	The American Psychiatric Association states in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, 2013) that 5% of children have ADHD.	https://www.cdc.gov/ncbddd/adhd/data.html	5% (Child)
6	A history of ADHD diagnosis by a health care provider increased by 42% between 2003 and 2011 (5% per year): 7.8% had ever had a diagnosis in 2003, 9.5% had ever had a diagnosis in 2007, 11.0% had ever had a diagnosis in 2011 (5% increase per year) The percentage of children 4-17 years of age taking medication for ADHD, as reported by parents, was: 4.8% in 2007 and 6.1% in 2011	https://www.cdc.gov/ncbddd/adhd/features/key-findings-adhd72013.html	11% (Child)

Other Sources

	Description	Web link/Source
1	ONS 2016 based subnational population projections & 2017 based estimates for CCGs and Local Authorities	https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections
2	East Berkshire Local Transformation Plan for Children and Young People's Mental Health and Wellbeing, October 2018 - October 2019	https://www.eastberkshireccg.nhs.uk/
3	Undiagnosed autism: As most people get diagnosed with autism during late toddler, early primary school years, it is expected that adults in their 40s and over (60% of adult population) are mostly undiagnosed.	https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-in-the-u-s/ https://www.autism.org.uk/about/diagnosis/criteria-changes.aspx
4	Undiagnosed ADHD: Currently about a third of children are diagnosed, while for adults it is about 7-8%, of expected prevalent population.	http://www.adhdaction.org/
5	4 times as many boys as girls are diagnosed with autism	www.autism.org.uk
6	3 times as many boys as girls are diagnosed with ADHD	https://www.caba.org.uk/
7	Most cases of ADHD are diagnosed when children are 6 to 12 years old.	https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/
8	The median age at autism diagnosis in the whole sample was 55 months , in line with figures reported by the CDC in the US (2014), but much lower than the 82 months reported by the UK study of 86 children (Williams et al. 2008), and the 66–71 months reported in a previous UK study of 267 children (Latif and Williams 2007).	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4860193/
9	Average age of referral for autism, based on actual BHFT data is between 7 and 8 years old	Referral data obtained from service heads of Community Pediatrician, CAMHS and Adult autism/ADHD Services at BHFT.
10	Autism is much more common than many people think. There are around 700,000 people on the autism spectrum in the UK – that's more than 1 in 100 ¹ . If you include their families, autism is a part of daily life for 2.8 million people.	https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx

Appendix 2 Population needs analysis, prevalence and demand

Contents

- East Berkshire population
- Expected prevalence based on current population
- Undiagnosed population
- Life costs
- Current demand: from referral to waiting list (Summary East Berkshire)
- Current demand: from referral to waiting list (Summary per age group)

For further detail (not included in the appendix) on health & care needs, population, prevalence, demand and life costs, see Deliverable 1 and 2.

Population estimates

This chart shows the population breakdown of the individual local authorities and East Berkshire as a whole.

The age bands relate to the relevant age grouping used in relation to autism and ADHD:

- Aged 0-4: pre-school children
- Aged 5-16: school children
- Aged 17-18: transition age to adults
- Aged 19-24: young people
- Aged >24: other adults

Slough have a relatively young population with 27.2% aged 0-16, compared to Bracknell Forest and Windsor & Maidenhead, who are showing 22% and 21.6% aged 0-16 respectively.

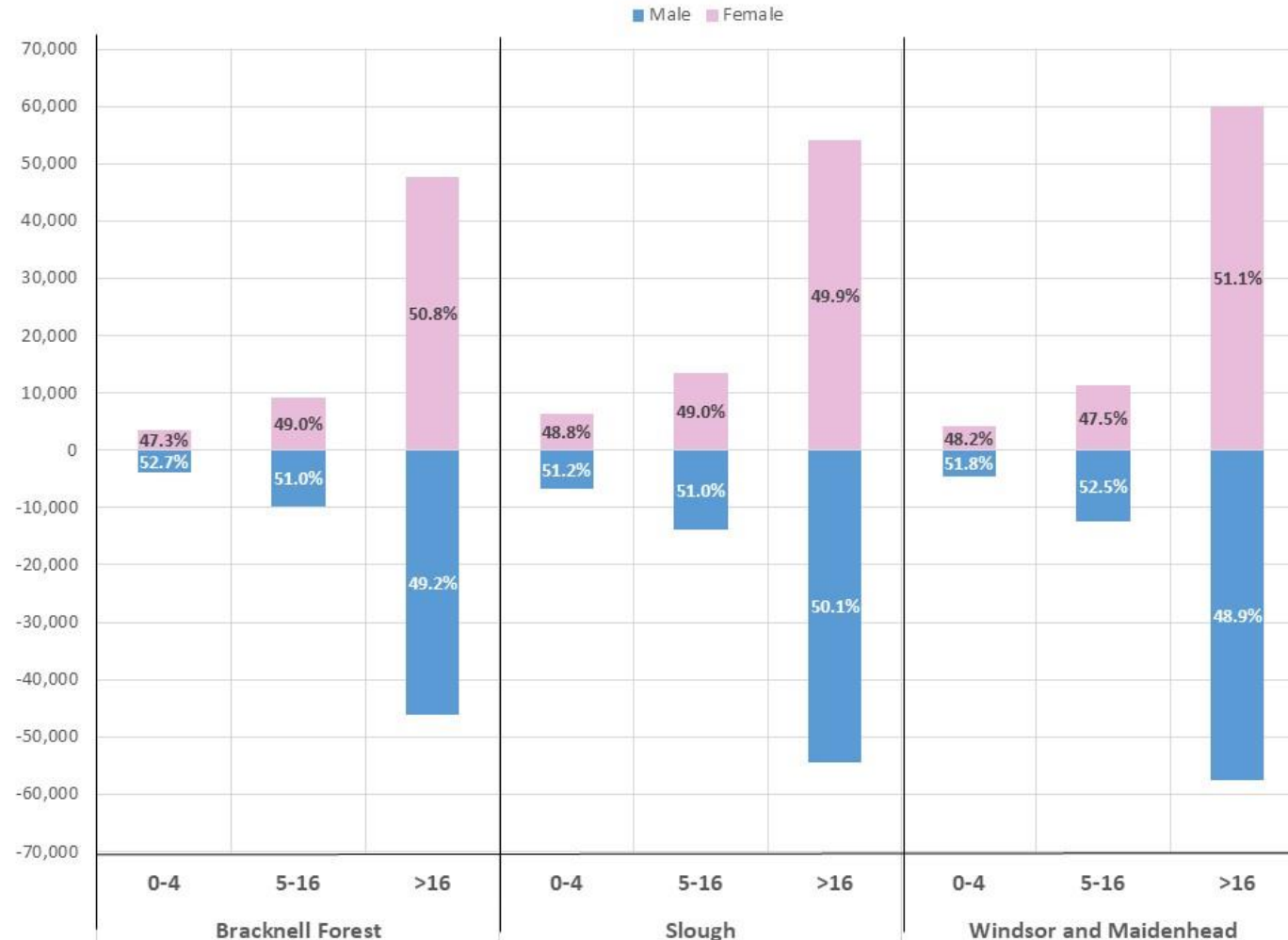
It is important that the above population breakdown is reflected in the amount of budget that's allocated to for example assessment and diagnosis which tends to happen early in life. This will also prevent waiting list to grow unnecessarily.

2017 Population Age Distribution East Berkshire LAs (in thousands)



Population profile East Berkshire geographies split by age and gender

Population Estimates 2017: Gender breakdown by ageband for each Local Authority



The chart on the left shows the gender break down for local authority populations. The children's age bands show a higher percentage of boys than girls. Combined with the fact that boys are 3 to 4 times as likely to be diagnosed with autism and ADHD; and that girls with autism may require different treatment than boys (see below) this needs to be reflected in the care provided.

Why more boys than girl?

Autism.org.uk gives a number of reasons why boys are more likely to be diagnosed:

- That the diagnostic tests for women should be modified as they are currently based on the male profile
- That autism can be considered as an extreme of the normal male profile
- That genetic differences mean that girls are less likely to inherit autism than boys
- That men and boys tend to be more susceptible to organic damage which is related to autism
- That women and girls are better at masking or camouflaging their difficulties
- That autism traits in girls are under-reported by teachers

<https://www.autism.org.uk/about/what-is/gender.aspx>

Source: ONS

Expected prevalence - summary comparing local and benchmark for autism and ADHD

Local Authority	Segment	Population (2019)	Expected Prevalence autism 2019					Expected Prevalence ADHD 2019				
			Local		Benchmark		Variation (No.)	Local		Benchmark		Variation (No.)
			%	No.	%	No.		%	No.	%	No.	
Bracknell Forest	Pre-school (<5)	7,358	0.25%	18	0.25%	18	0	0.00%	0	0%	0	0
	School (5-16)	19,244	1.17%	225	1.50%	289	64	5.00%	962	7.00%	1,347	385
	Adults (>16)	95,494	1.00%	955	1.50%	1,432	477	3.00%	2,865	4.00%	3,820	955
Slough	Pre-school (<5)	12,520	0.25%	31	0.25%	31	0	0.00%	0	0%	0	0
	School (5-16)	28,715	1.08%	310	1.50%	431	121	5.00%	1,436	7.00%	2,010	574
	Adults (>16)	109,437	1.00%	1,094	1.50%	1,642	547	3.00%	3,283	4.00%	4,377	1,094
Windsor & Maidenhead	Pre-school (<5)	8,643	0.25%	22	0.25%	22	0	0.00%	0	0%	0	0
	School (5-16)	24,170	1.06%	256	1.50%	363	106	5.00%	1,209	7.00%	1,692	483
	Adults (>16)	118,354	1.00%	1,184	1.50%	1,775	592	3.00%	3,551	4.00%	4,734	1,184
Other*	Pre-school (<5)	386	0.25%	1	0.25%	1	0	0.00%	0	0%	0	0
	School (5-16)	1,060	1.00%	11	1.50%	16	5	5.00%	53	7.00%	74	21
	Adults (>16)	10,811	1.00%	108	1.50%	162	54	3.00%	324	4.00%	432	108
NHS Berkshire East CCG	Pre-school (<5)	28,907	0.25%	72	0.25%	72	0	0.00%	0	0%	0	0
	School (5-16)	73,189	1.10%	802	1.50%	1,098	296	5.00%	3,659	7.00%	5,123	1,464
	Adults (>16)	334,096	1.00%	3,341	1.50%	5,011	1,670	3.00%	10,023	4.00%	13,364	3,341
Total		436,192	0.97%	4,215	1.42%	6,182	1,966	3.14%	13,682	4.24%	18,487	4,805

The benchmark provides a comparator prevalence which indicates how many extra people expected to be living with autism/ADHD. The difference between local and benchmark is a measure of potential unmet need

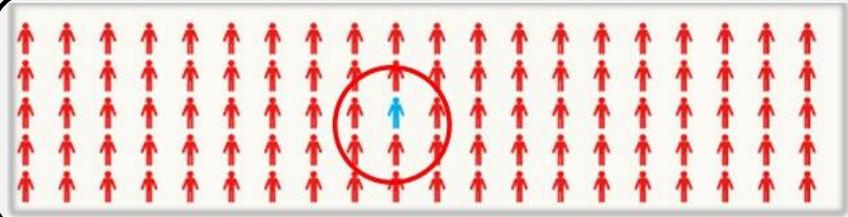
Applied benchmarks:

- 1.5% for autism both children & adults; and
- 7% and 4% for ADHD in children and adults respectively

Total prevalence variation for:

- autism equates to 1,966 people
- ADHD equates to 4,805 people

Expected prevalence autism: comparing local rate and benchmark



Currently 1 in 100 of people (1.0%) have autism compared to benchmark of 1 in 66 (1.5%)*

Expected Prevalence:

Local

Benchmark

Difference



Bracknell Forest

1,198

1,739

541

Slough

1,436

2,104

668

RBWM

1,461

2,159

698

Other

120

179

59

Berkshire East

4,215

6,181

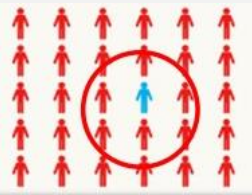
1,966

East Berkshire CCG
total expected
prevalence gap autism:

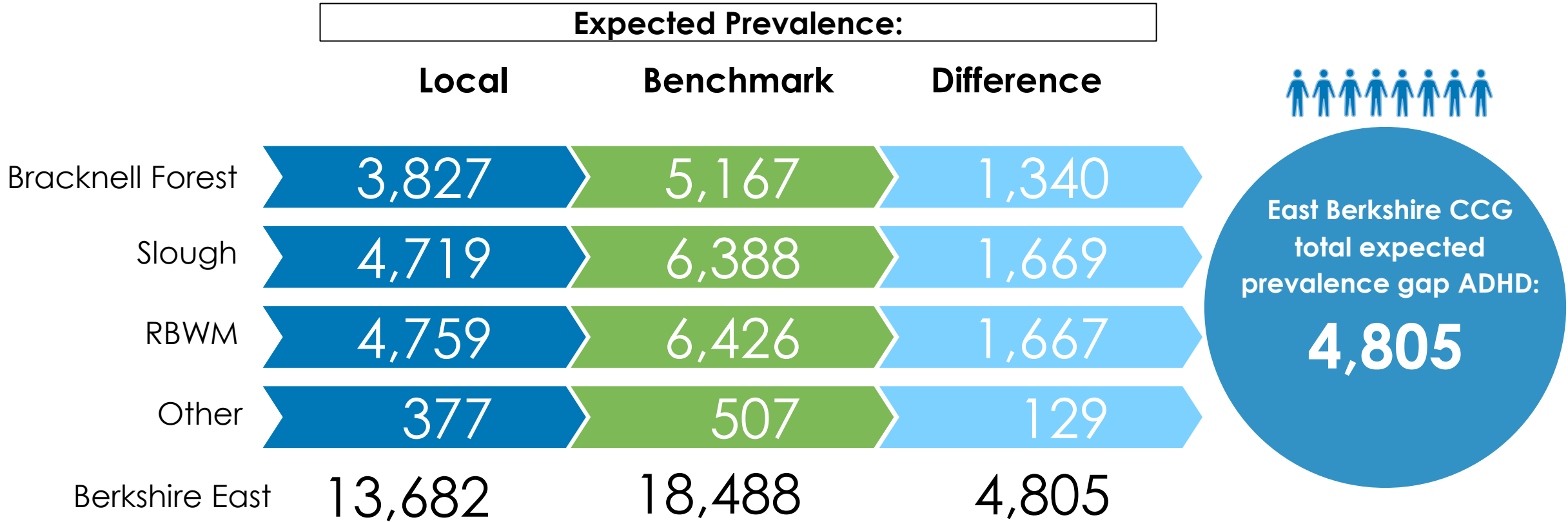
1,966

* Based on national studies in USA and Canada

Expected prevalence ADHD: comparing local rate and benchmark



Currently 1 in 32 (3.1%) of people have ADHD compared to benchmark of 1 in 24 (4.2%)*



* Based on outcome prevalence study, average taken across children and adults for display purposes only.

Summary of undiagnosed population for autism/ADHD in East Berkshire



Based on Local Expected Prevalence Rates, an estimate of number of undiagnosed is presented below

Pathway	Age Group	Expected Prevalence based on Local/UK rates	Expected Undiagnosed
autism	Pre-school (<5)	72	0 ¹
	School children (5-16)	802	0 ²
	Adults (>16)	3,341	2,000 ³
ADHD	Pre-school (<5)	0	0
	School children (5-16)	3,659	2,439 ⁴
	Adults (>16)	10,023	9,221 ⁴

¹ No estimate available for this age group but any undiagnosed will appear on the radar as soon as they go to primary school

² Prevalence rates for this age group were based on numbers obtained from local JSNA's and equated to approximately 1% UK estimate prevalence which suggests that most children with autism are known to at least schools and are getting some sort of support.

³ This estimate is based on the fact that autism was not included in disease classification systems until the 1980's and hence a large group of 40 years and older are likely to be undiagnosed with autism.

⁴ These estimates are based on research assuming that two thirds of children and 92% of adults are currently undiagnosed with ADHD.

Overview life cost search



No	Description	Name/Link source
1	There is a lot of research available on service use trajectory and life costs. Although the date (2011) of this article is some time ago, it is still the most complete because it takes into account autism with and without MH comorbidities (like ADHD). Apart from medical non-medical care costs, other life cost categories included are special education, loss of productivity of patient and/or parent, special living accommodation and respite care. The article hereby differentiates between children and adult who have different needs.	https://jamanetwork.com/journals/jamapediatrics/fullarticle/1879723
2	The average annual life course costs for a patients living with ADHD varies between £69,000 and £130,000. These are averages across a life time and don't distinguish between age groups. Overall 44% relates to education, 34% employment and 21% health care.	https://www.centreformentalhealth.org.uk/sites/default/files/2018-11/costs_of_ADHD.pdf
3	Average life costs for children in mental health vary between £11,000 and £59,000. These costs fall to a variety of agencies (e.g. education, social services and youth justice) and also include the direct costs to the family of the child's illness.	Reference included in BHFT CAMHS 2018/19 Service specification, obtained from East Berkshire CCG
4	If autism/ADHD not treated early enough, these patients may move into Mental Health services. Annex of this document provides a listing of 'Costs of different mental disorders across the life course'. This includes conduct disorder, anxiety, depression, smoking, alcohol misuse etc (many of these include the costs of crime to society etc)	https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215808/dh_123993.pdf
5	Across England and Wales, it cost an average of £37,543 a year to keep a prisoner in jail in 2017/18 which equates to £100 per night. Highest cost found in England equates to about £70,000 pa. Loss of productivity after prison will increase these costs even more.	https://www.chroniclive.co.uk/news/north-east-news/hmp-frankland-most-notorious-prisoners-15332522

Life Costs



The table below presents the average annual life costs (MIN and MAX value) for an autism, ADHD, MH patient both adults and children, based on life course cost. These are based on the findings of the literature search on the previous slide.

Group	Min	Max	Comment
autism - Child ¹	£30,000	£42,000	66% relates to special education
autism - Adult ¹	£50,000	£87,000	Max value assumes autism in combination with MH/LD comorbidity, of which 50% relates to accommodation, 25% to productivity loss/employment
ADHD - Child ²	£45,000	£85,000	66% to 80% relates to special education
ADHD - Adult ²	£32,000	£79,000	56% to 78% relates to productivity loss/employment
MH/LD – Child ³	£11,000	£59,000	These costs (in excess of normal costs) fall to a variety of agencies (e.g. education, social services and youth justice) and also include the direct costs to the family of the child's illness.
MH/LD – life course ⁴	-	-	If autism/ADHD not treated early enough, these patients may move into Mental Health services. Annex of below document ⁴ provides a listing of 'Costs of different mental disorders across the life course'. This includes conduct disorder, anxiety, depression, smoking, alcohol misuse etc (many of these include the costs of crime to society etc)
Prison ⁵	£37,543	£70,000	Across England and Wales, it cost an average of £37,543 a year to keep a prisoner in jail in 2017/18 which equates to £100 per night. Highest cost found in England equates to about £70,000 pa.

What does this mean in terms of life cost savings?

- Every child with autism/ADHD will have unique talents, it is up to the parents to ensure that their child is diagnosed early and receives the right kind of help, so their child can truly tap into their potential and live independently. This should also reduce the loss of productivity, loss of income/employment and dependent living in later adult life. Considering these factors ^{1, 2} represent the majority of life costs in adults for both autism and ADHD, this could imply a large cost saving.
- Children whose treatment for autism/ADHD is delayed are more likely (1) to develop learning difficulties, and/or (2) to grow up with issues ranging from sensory to cognitive to behavioural mental health problems. The life costs of child in mental health patients presented in the table are in excess of normal costs, i.e. the costs related to mental health and youth justice could potentially be avoided if children are diagnosed as early as possible.
- A high cost component in total societal costs for mental health problems in general relate to behaviour problems, alcohol misuse, smoking, crime etc ⁴. **For example:** *"Cost of crime attributable to adults who had conduct problems in childhood is estimated at £60 billion a year in England and Wales, of which £22.5 billion a year is attributable to conduct disorder and £37.5 billion a year to sub-threshold conduct disorder."* Children with autism/ADHD, if not diagnosed early, may end up contributing to this high cost estimate.
- There will be a strong overlap between these unit costs as patients with autism and/or ADHD are very likely to have MH comorbidities. Considering the unit costs however, there is an incentive to diagnose and detect people earlier, preventing them from moving into mental health or learning disabilities, or even the judicial system, and incurring those extra costs.

Demand: From Referral to Diagnosis

Introduction

- This section shows a picture of demand from initial referral to diagnosis for autism and ADHD split by the different age groups that each have different needs and are currently referred to different services:
 - Children under 5 with a suspected diagnosis get referred to the Community Paediatrician for assessment by a MAG (Multi Agency Group) or ADOS (individual assessment).
 - Children between 5 and 17 with a suspected autism/ADHD diagnosis are referred to CAMHS Autism/ADHD team at Berkshire Healthcare for assessment and follow up with autism assessment only.
 - Adults are referred to Adult Mental health services at Berkshire Healthcare, for ADHD these referrals includes newly diagnosed, already diagnosed needing medication/annual review, and young adults transitioning from CAMHS.
- Across all age bands only 1 in 3 referrals are actually diagnosed with autism and/or ADHD. This low ratio is caused by low levels of acceptance and opt-in for referrals, referrals put on waiting list due to limited capacity, high levels of people that do not attend appointments, and only 80% of patients getting diagnosed at assessment.
- Caseload and waiting list for all groups are ever increasing, showing that the teams are working at maximum capacity. Waiting times vary between 12 and 24 months for Children and Adults.
- Total number of people on the different waiting lists at the end of 2018/19 equals 1,117 patients. Assuming current DNA rates and expected diagnosis at assessment, 800 of these patients are expected to be diagnosed and treatment is delayed (between 12 and 24 months).
- Above statistics show potential efficiency savings could be made.

Under 5s: Summary autism referrals & waiting lists in 2018/19

- Total referrals for 2018/19 equate to approx. 268 of which 95% is accepted and get a preliminary appointment (254). Of the latter 80% (203 patients) get their diagnosis of autism confirmed.

Local Authority	Total referrals (2018/19)	Accepted Referrals (in 2018/19)	Caseload (at Q4 2018/19)	Appointments 2018/19 (incl DNA)**	Appointments 2018/19 (First; Fu)	Diagnosed with autism (80%)	Waiting list (at Q4 2018/19)
Bracknell Forest	93	88	48	191	186 (86;100)	69	48
Slough	114	108	136	375	355 (102; 253)	82	43
RBWM	61	58	71	142	138 (56; 82)	45	35
Berkshire East	268	254**	255**	708	679 (244; 435)	195	126*

* This waiting list only includes referrals that were made in 2018/19 so will be underestimated

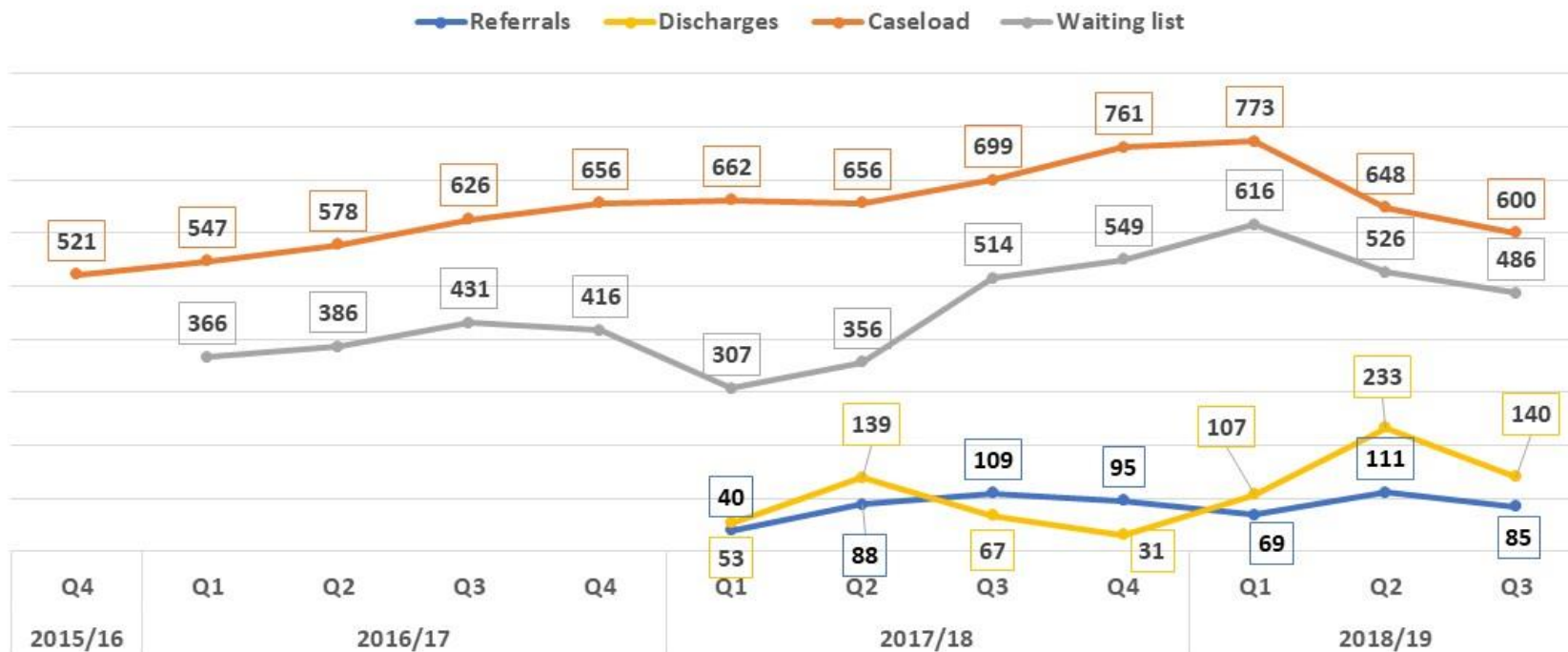
** approx. 80% of caseload/referrals relates to MAGs

Summary autism diagnosed in Children (5 and over) in East Berkshire:



Just over 1 in 100 children currently have autism which equates to approx. 800 cases in Berkshire East

ASD - East Berkshire CCG activity to CAMHS at BHFT (5-18 year olds)



Total **referrals** to assessment in most recent 12 months was **360**; **324 patients** had an **appointment of which 20 DNA**

In the same period total of **511 patients** got **discharged**.
Mainly due to caseload review.

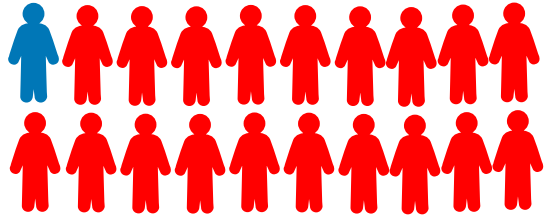
In 2018/19 total autism **caseload** equals **625** patients of which **512 on the waiting list**

Total with expected autism diagnosis (assumption 80%) of

- Referrals seen: 239
- On waiting list: 379

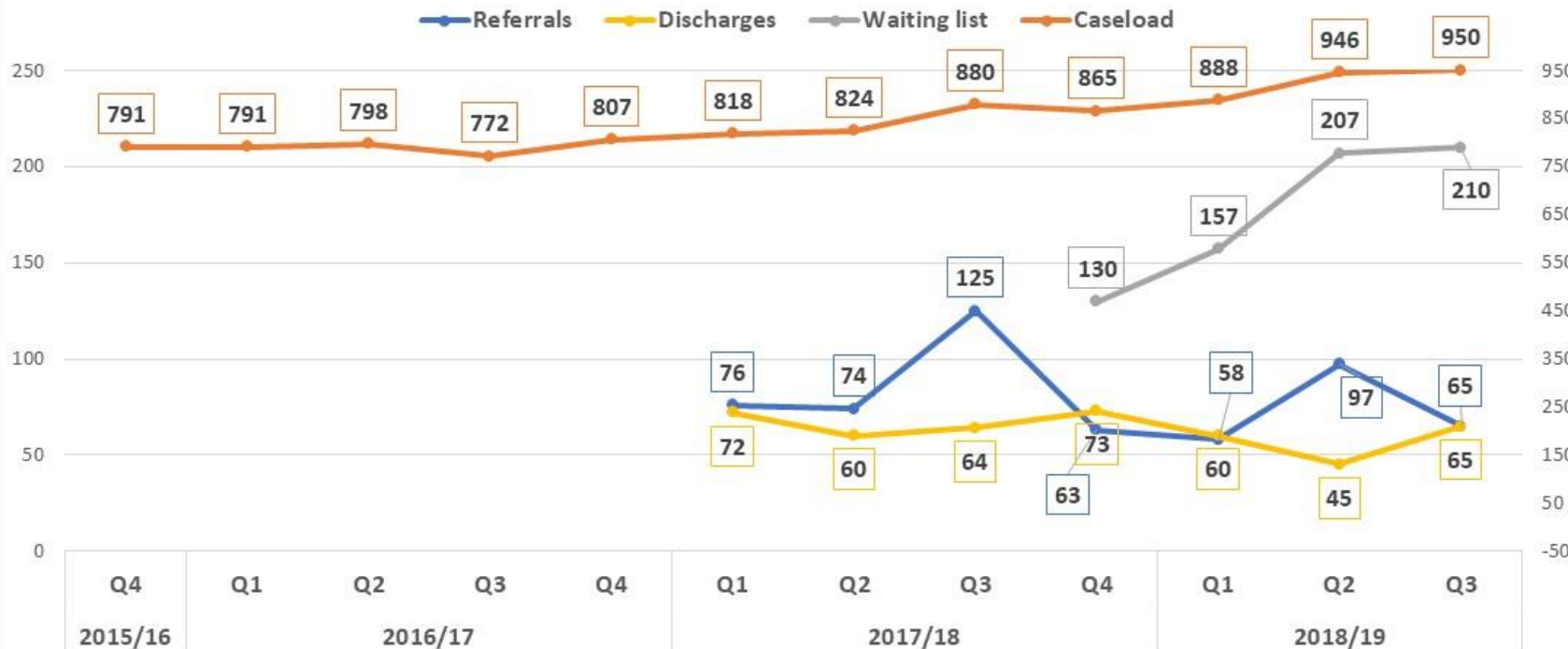
LA	Referrals Diagnosed	Waiting list Diagnosed
Bracknell	99	141
Slough	65	98
RBWM	76	140
Total	239	379

Summary ADHD diagnosed in children (5 and over) in East Berkshire:



1 in 20 children currently have ADHD* which equates to approx. 3,650 cases in Berkshire East

ADHD - East Berkshire CCG activity to CAMHS at BHFT (5-18 year olds)



Total **referrals** to assessment in most recent 4 quarters equals **283**; **250 patients** had an **appointment**, of which **43 DNA**

In the same period **243 patients** got **discharged**.

In 2018/19 total ADHD **caseload** equals **916** patients of which **208 on the waiting list**

Total with expected ADHD diagnosis (assumption 80%) of

- Referrals seen: 166
- Waiting list: 138

LA	Referrals Diagnosed	Waiting list Diagnosed
Bracknell	59	49
Slough	39	32
RBWM	67	56
Total	166	138

*estimate based on research

Summary autism diagnosed in adults in East Berkshire:



Just over 1 in 100 adults currently have autism which equates to approx. 3,350 cases in Berkshire East

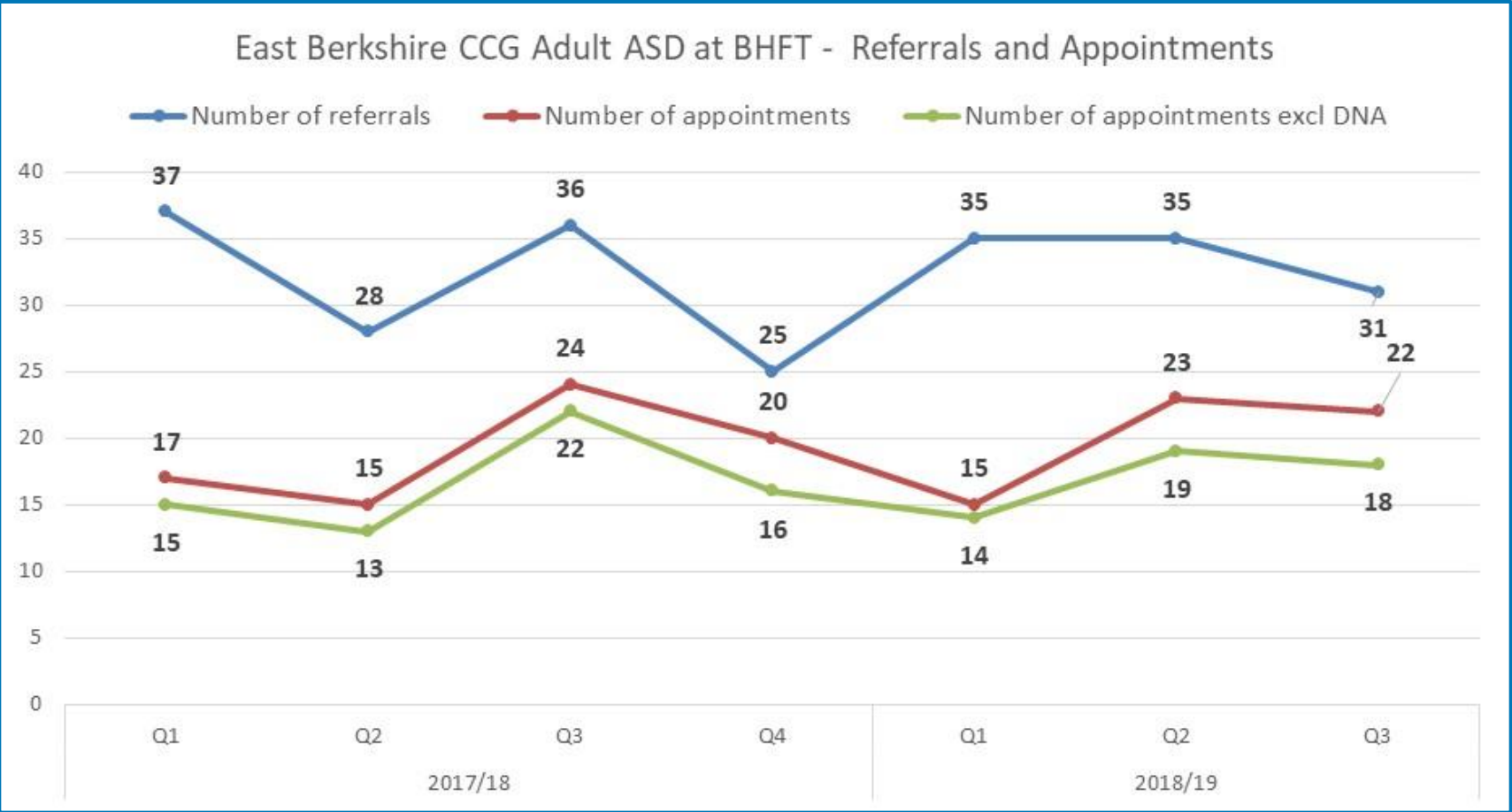
Total **referrals** were **126** in most recent 12 months of which **123** for assessment

80 patients had an appointment for **assessment** previous 12 months (of which **14** DNA's)

Currently for autism there are **135** people on the waiting list

Total expected diagnosed with autism (assumption 80%) of

- Referrals seen: 54
- Waiting list: 99



LA	Referrals Diagnosed	On Waiting list Diagnosed
Bracknell	16	29
Slough	18	34
RBWM	20	36
Total	54	99

Summary ADHD diagnosed in adults in East Berkshire:





1 in 33 adults currently have ADHD* which equates to approx. 10,025 cases in Berkshire East

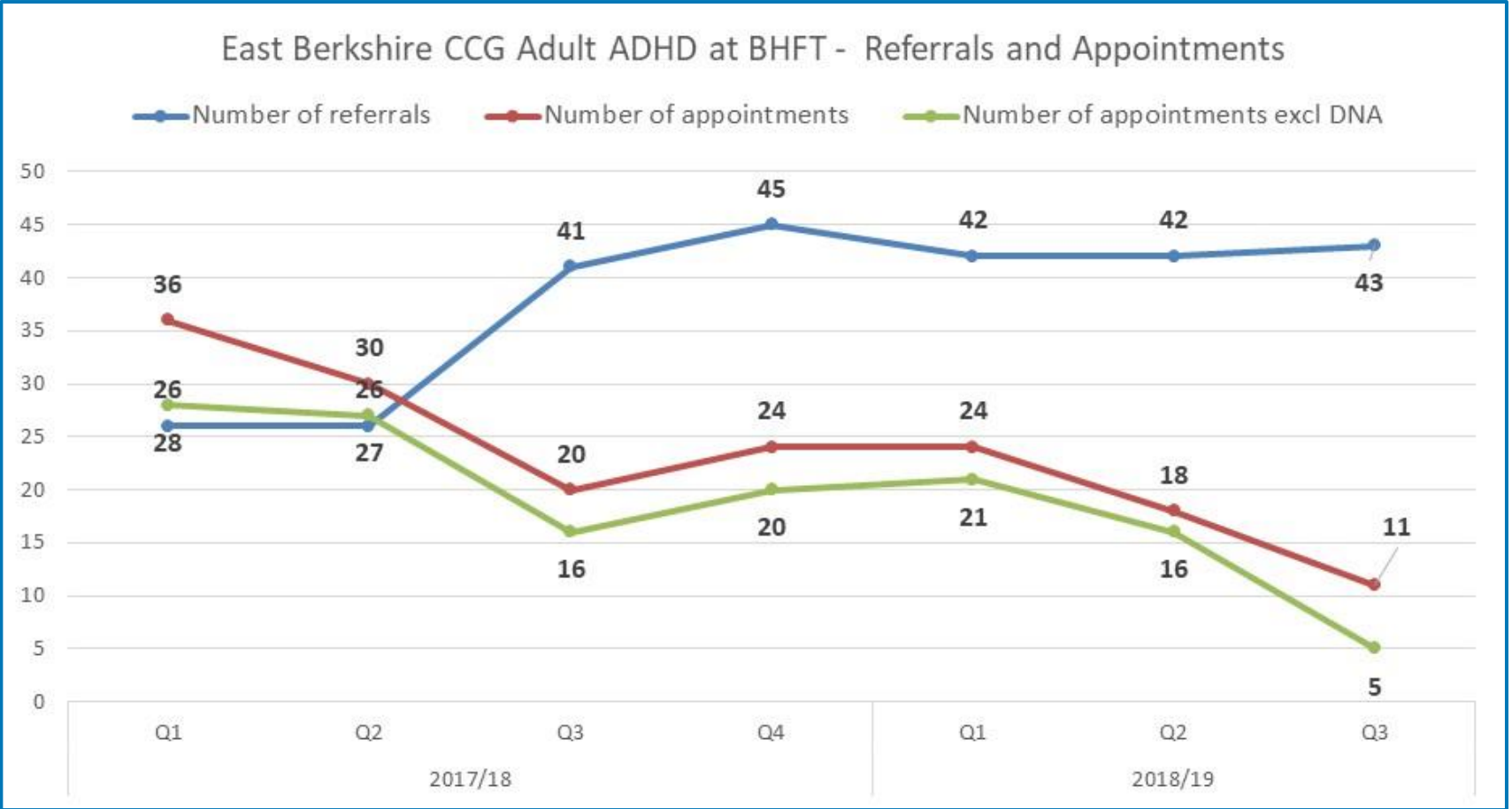
Total **referrals** was **257** in most recent 4 quarters of which **172** were for psychological assessment

77 patients had an appointment for assessment in the most recent 4 quarters (**of which 15 DNA's**)

Currently for ADHD there are **136 people on the waiting list**

Total expected diagnosed with ADHD (assumption 80%) of

- Referrals seen: 50
- Waiting list: 88



LA	Referrals Diagnosed	Waiting list Diagnosed
Bracknell	15	26
Slough	17	30
RBWM	18	32
Total	50	88

*estimate based on research

Appendix 3 – Future prevalence and demand

Projection forward - Methodology

- The following slides will show the projected prevalence for autism and ADHD over the next 20 years that will dictate demand to services.
- Projected prevalence is calculated by applying subnational 2017 based population projections that were obtained from ONS. These projections have been applied separately by age band (under5s, over 5s and adults) and Local Authority (Bracknell, Slough and RBWM) for the years +5,+10,+15 and +20 from now and then aggregated up to East Berkshire level.
- Input: expected prevalence based on local rates and benchmark, split by diagnosed and undiagnosed
- Outputs have been presented separately for autism Children, autism Adults, ADHD Children and ADHD Adults.

Summary of undiagnosed population for autism/ADHD in East Berkshire, 2019

Based on Local Expected Prevalence Rates, an estimate of number of undiagnosed is presented below

Pathway	Age Group	Expected Prevalence 2019 based on			
		Local/UK rates			Benchmark Rate
		Diag	Undiag	Total	
autism	Pre-school (<5)	72	0 ¹	72	72
	School children (5-16)	802	0 ²	802	1,098
	Adults (>16)	1,341	2,000 ³	3,341	5,011
	Total	2,215	2000	4,215	6,181
ADHD	Pre-school (<5)	0	0	0	0
	School children (5-16)	1220	2,439 ⁴	3,659	5,123
	Adults (>16)	802	9,221 ⁴	10,023	13,364
	Total	2,022	11,660	13,682	18,488

¹ No estimate available for this age group but any undiagnosed will appear on the radar as soon as they go to primary school

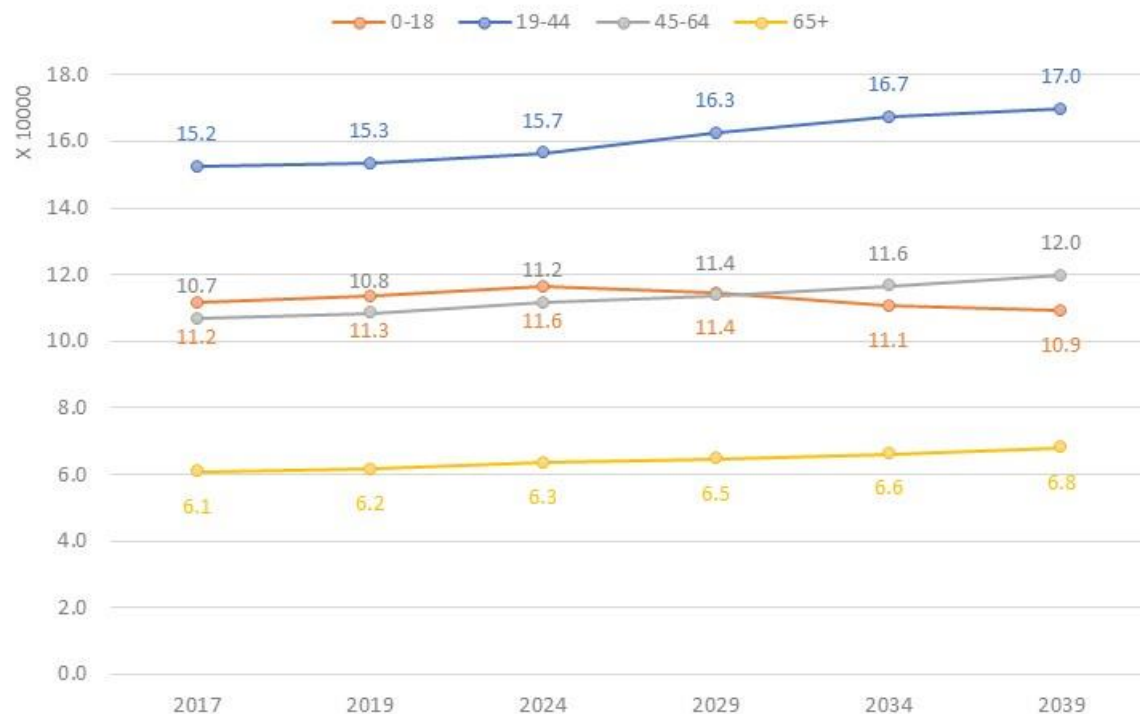
² Prevalence rates for this age group were based on numbers obtained from local JSNA's and equated to approximately 1% UK estimate prevalence which suggests that most children with autism are known to at least schools and are getting some sort of support.

³ This estimate is based on the fact that autism was not included in disease classification systems until the 1980's and hence a large group of 40 years and older are likely to be undiagnosed with autism.

⁴ These estimates are based on research assuming that two thirds of children and 92% of adults are currently undiagnosed with ADHD.

Population projections – NHS East Berkshire CCG

Population Change NHS East Berkshire CCG All ages



The over 18s will be growing by about 0.5% on average per year over the next 20 years.

If the autism/ADHD prevalence rate doesn't change, as many literature suggests, we expect to see similar patterns in the prevalent autism/ADHD populations, but with the child population declining, this means that potentially health care burden shifts from children to adults. (see next slide).

The 0-18 age group in East Berkshire is expected to initially grow by 0.5% per year over the next 5 years, and then start to decline by on average 0.4% per year until 2039 (20 years from now). The rapid increase in the next 5 years is driven by the 11 to 16 year olds which also covers the challenging transition from primary to secondary school.

Population Change NHS East Berkshire CCG by 0-18 broken down by Childrens agebands

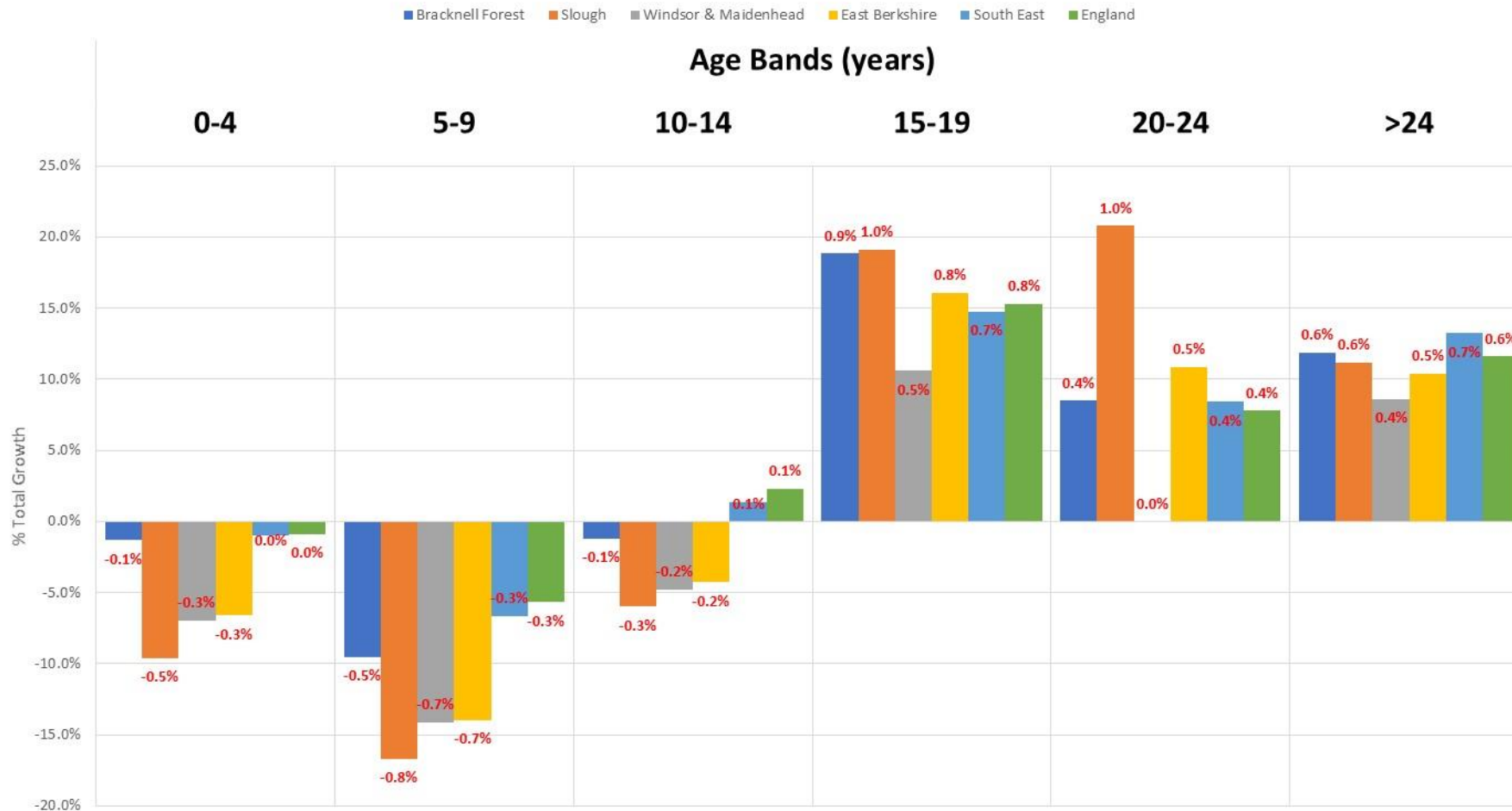


Source: ONS

Total population growth between 2019 and 2039

(Red labels represent average growth per annum)

Total % Population Growth between 2019 and 2039 by Ageband



- Population in the age bands for school children is declining on average (following regional and national trends)
- The adult population is showing a clear average increase over the next 20 years.
- If prevalence of autism/ADHD does not change, this may indicate a potential shift of health and care burden from children to adults.

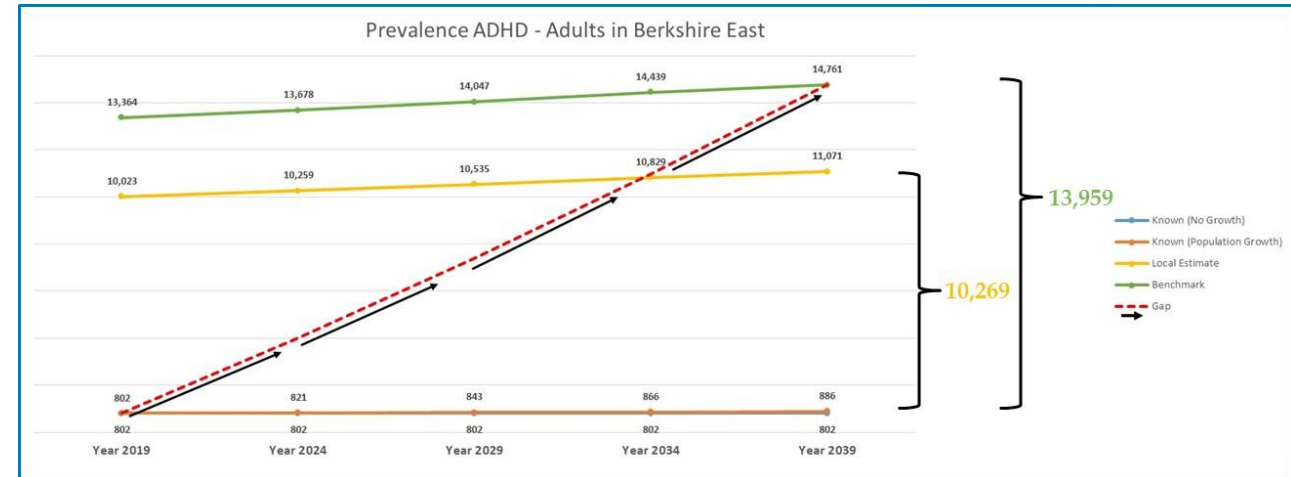
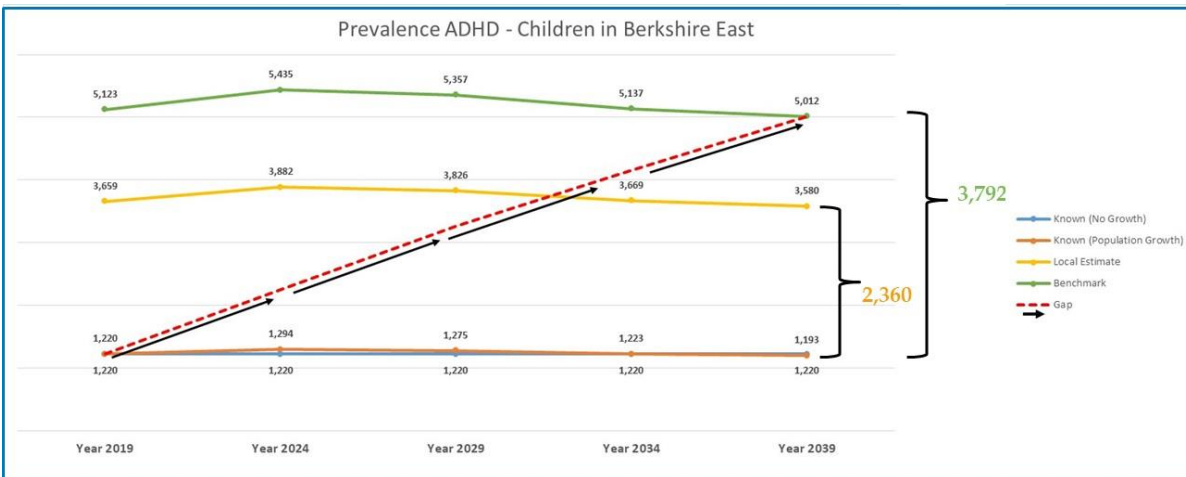
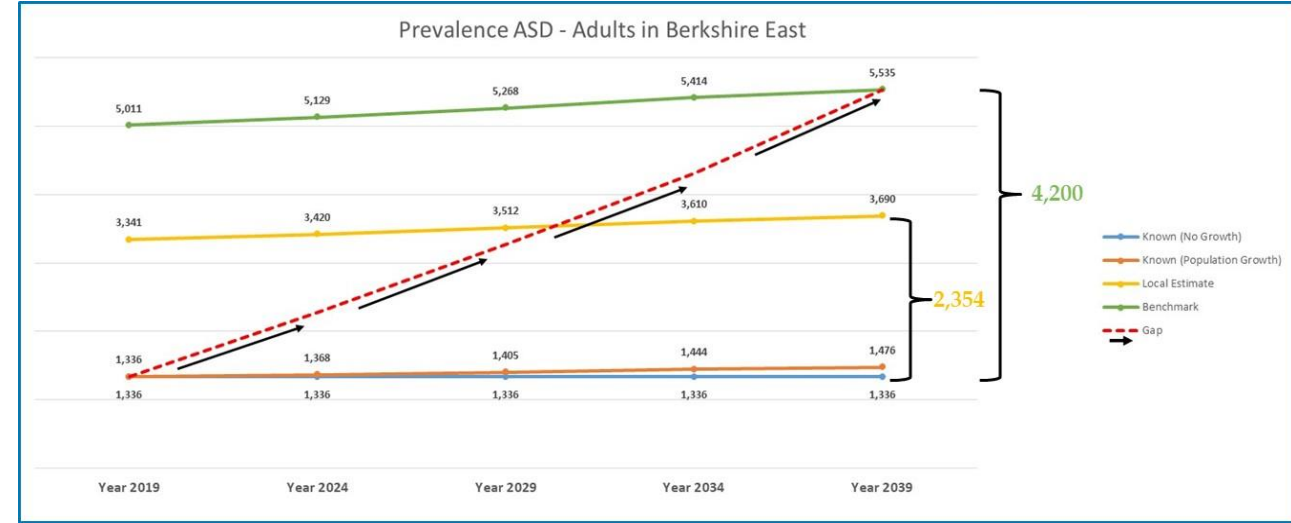
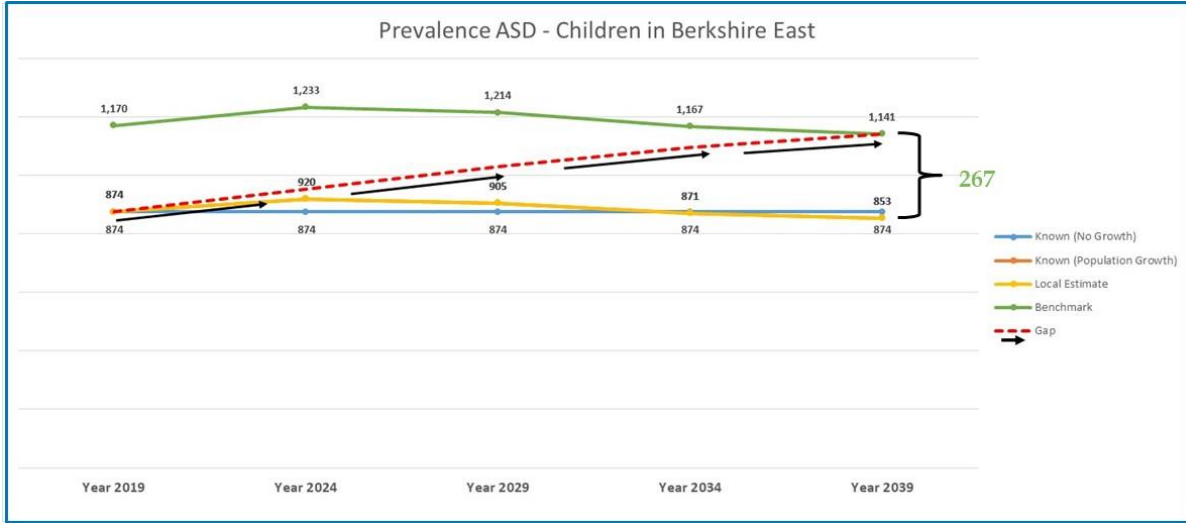
Projections Forward - Output

See summary on next slide

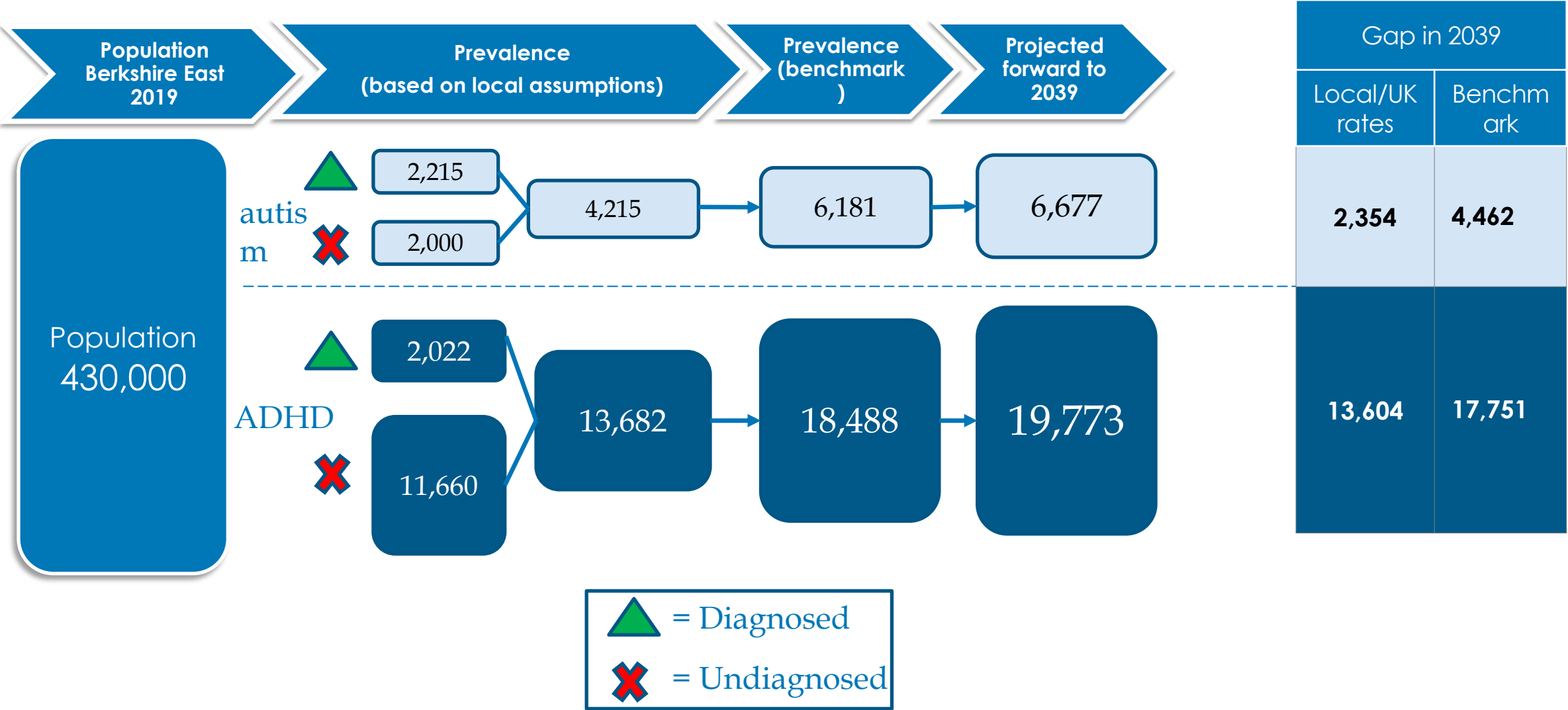


Each chart will show a number of lines:

- what the diagnosed/known population will look like over the next 20 years if no growth applied (**blue line**)
- what the diagnosed/known population will look like over the next 20 years if population projections applied (**orange line**)
- a **yellow line** representing estimate of expected total prevalence based on local and national information, and will include the undiagnosed population
- a **green line** representing bench mark estimate of expected total prevalence



Summary future expected prevalence East Berkshire



Appendix 4 Description of local services, issues and inconsistencies

East Berkshire service description

Here is a description of current service provision:

Organisation	Category	Service description	Geographic area
Bracknell Forest Council	0-5 multi-agency assessment (Margaret Furby Wells Childrens Development Centre)	0-5 multi-agency holistic autism assessment. The team offers ongoing support to families. Training for parents of children up to the age of 9. The assessment team includes early years staff, SALT, OT (when available) community paediatrician who usually sees the child for an initial assessment before the 3 week assessment takes place. Child is assessed 1 morning over 3 weeks. The team tries to observe the child in a nursery setting – or any setting that would be most appropriate including their home). Family workers employed by the council work directly with families where appropriate. Family development workers will also refer to the service if needed. The team are part of the early intervention hub which meets every 2 weeks to discussed referred the families – managing in an MDT way. There are SALT drop in sessions at children's centres across the Bourgh and children identified in those sessions will be referred to the team if appropriate. At the centre, there are SALT and paediatrician drop in sessions, once per week SALT screening takes place. Children are also identified and referred to the team through an under 5's joint working physio groups – called Many Hands – joint assessments are carried out between SALT/physio and OTs. Dependent on need a group called Many Hands runs at the centre, this means children who are requiring services from a number of professions, e.g. physio, SALT, CDC are invited to the group and can be seen by all services. These sessions are run once a week. The team provide joint training with SALT for nurseries – Who, What and Why?	Bracknell
Berkshire Healthcare NHS Foundation Trust (BHFT)	0-5 multi-agency diagnosis	Preliminary consultant assessment, Multi-agency groups providing 0-5 assessment and diagnosis staff include community paediatrician, SALT, OT, SEN <ul style="list-style-type: none"> Children under 5 with a suspected autism diagnosis in Berkshire East are referred to the community paediatrician at BHFT for assessment. After a preliminary appointment that needs to take place within 18 weeks, children with a suspected diagnosis are then investigated by either a: <ul style="list-style-type: none"> Multi Agency Group (MAG) consisting off Consultant Psychiatrists, Speech and Language therapists and assistants; or ADOS (Autism Diagnostic Observation Schedule) which is an individual assessment involving a consultant paediatrician and a SLAT ADOS involves a single 3 hour appointment, where the MAG group consists of 3 appointments and one care Plan appointment. Before assessment patients are placed on awaiting list. Average waiting time for MAG is 6 to 8 months, and for ADOS 12 to 18 months. Achieving for Children deliver in RBWM and Integrated Support Service for Slough	Slough and Windsor and Maidenhead
BHFT CAMHS	Children, Young People & Families (5-17)	The treatment paths for autism and ADHD are as follows: <ul style="list-style-type: none"> ADHD (attention deficit hyperactivity disorder) – assessment and annual medication review autism (autistic spectrum disorder) – diagnosis only Patients are referred to CAMHS with a suspected diagnosis of autism or ADHD (or both) first receive an initial assessment at Central Point of Entry. All patients that arrive at CPE go on the CPE waiting list. After initial assessment at CPE, all referrals that are accepted are sent from Central Point of Entry (CPE) to ADHD or AAT (The Autism Assessment team) and are placed on a waiting list prior to being seen. The Autism team have two waiting lists – Priority and Routine. Priority assessments include CYP who are LAC or who have CP Plans, CYP who are at high risk due to offending behaviours, CSE, highly suicidal or risk taking behaviours or who have been excluded from school. Approximately 5.2% of East referrals are placed on the priority waiting list meaning they are seen in or around 3 months if all documentation is returned. Significant numbers of children may be on both autism and ADHD caseload/waiting list. Based on anecdotal evidence, careful estimates show a couple of hundred children waiting for assessment by both teams. ADHD and autism cases with more complex needs and other comorbidities will end up on the caseload of the Specialist Community Team (SCT). autism patient are discharges after assessment, and ADHD patients are offered follow up appointments for medication support and review.	East Berkshire

East Berkshire service description

Organisation	Category	Service description	Geographic area
Autism Berkshire	Children, Young People, Adults & Families	The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals. Services include: <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers 	Berkshire
Parenting Special Children	Parents & Carers	PSC run various courses and workshops & Parenting Programmes throughout the year, such as: <ul style="list-style-type: none"> - Pre & Post Autism Workshops - Pre & Post ADHD Workshops - Time Out for ADHD - Time Out for Autism - Anxiety & Autism Workshop - Sleep Workshops - Pre & Post Diagnosis Support - Looked After and Adopted Children with Special Needs - Time out for Special Needs - Parenting Support - Bespoke Training - Autism Girls Monthly Speaker Events 	Bracknell, Slough, Windsor and Maidenhead
The Autism Group	Children, YP & Families & Carers	The Autism Group offers free Parent Support and Social groups, parent training sessions and a home visit service for residents in the Boroughs of Windsor and Maidenhead, Slough and Bracknell. These services are offered to parents of children and young people of any age who either have a diagnosis of an autism spectrum condition or are on the diagnosis pathway awaiting assessment	Bracknell, Slough, Windsor and Maidenhead
Various Local offer	Children, YP, Adults & Families	There are 23 other voluntary sector groups & providers across Bracknell Forest that offer support for children, young people, adults & families with autism/ADHD	Bracknell
Various Local offer	Children, YP, Adults & Families	There are 26 other services provided by voluntary sector groups	Windsor and Maidenhead
Various Local offer	Children, YP, Adults & Families	There are 70 other voluntary sector groups across Slough that offer support for children, young people, adults & families with autism/ADHD	Slough

East Berkshire service description

Organisation	Category	Service description	Geographic area
Achieving for Children - AFC	Children, Young People & Families	Children's services improvement - developed an improvement package to support local authorities in raising the quality and performance of children services in the area. AFC are working with a number of authorities across the country. Services for schools – AFC provide extensive range of services for schools, including: school improvement and curriculum support, governor support, educational psychology, online safeguarding advice, school business support, school workforce development. Early help intervention -AFC take a perspective approach to working with children and their families. AFC have developed a package of support to help local authorities to rethink their approach to early help services while improving outcomes that children. Social care - AFC provide a full range of children's social care services. AFC support their social workers to undertake creative methods of intervention to ensure that the voice of the child is at the centre of the service development. Windsor and Maidenhead have a autism lead as part of the early help team the role supports families pre and post diagnosis. There are also 2 SENCOs who are part of the early help team and they support SENCOs and schools across the borough. SHINE is also delivered in schools for those with autism.	RBWM (Also covers Kingston and Richmond Councils)
Slough Borough Council	Children, Young People, families	For parents of pre-school children with a diagnosis of an autism spectrum disorder SBC offer support and training through the National Autistic Society EarlyBird Programme. For parents of children aged 4–8yrs, with a diagnosis of an autism spectrum disorder SBC offer support and training through the National Autistic Society EarlyBird Plus Programme. EarlyBird Outreach worker. Support for children and advice about the EarlyBird Programmes is available to nurseries and families. For some children with a Statement of Special Educational Needs, there are Specialist Resource Bases at some schools. The Autism service is also able to provide Outreach support to schools in the Borough, through: In-service training, half termly surgeries, visits to specific children, written reports, advice on management issues, attendance at Annual Review meetings, support for social understanding and guidance on appropriate resources and relevant publications.	Slough
Bracknell Forest Council	Adults & Families	For 0-5 s (see earlier slide) Bracknell Forest have a specialised team that supports adults with a primary diagnosis of autism. The team is called the Community Team for People with Autistic Spectrum Disorder. The team supports Adults who have been diagnosed with autism and their carers who are resident in the Bracknell Forest area may be eligible for support. The team has a nominated person working with in CMHT and they work closely with psychology and the psychiatrist. There is also a social worker based in the LD team who support people with Autism. The team carries out an assessment of both individuals and carers wherever they have needs, regardless of whether they are expected to be eligible for support from the council. The support provided covers a wide range of needs and includes: <ul style="list-style-type: none"> • a carer assessment and support plan • person-centred planning • community integration into mainstream services • support with the housing process • communication skills support • new skills development • approaching adulthood • independent advocacy • signposting or referral to relevant services • social group The team are trying to capture those coming up for retirement. The team also provides training for police, housing and libraries – the library has a quiet hour once a week.	Bracknell

East Berkshire service description

Organisation	Category	Service description	Geographic area
BHFT	Adult - ADHD	<p><u>Referral to assessment:</u></p> <p>The referrals coming in for ADHD consist of a mix of patients requiring first assessment, medication support and/or needing an annual review</p> <ul style="list-style-type: none"> New Adult Diagnosis Referral <ul style="list-style-type: none"> New referrals go through triage & MDT first After screening, all patients who have been accepted and have opted in go to the waiting list At assessment, psychology will determine a diagnosis, Diagnosis is followed by a post-diagnostic session, psychiatry appointment, Possible that following diagnosis there may be several appointments with a prescriber for (after a short medical wait) and put on the annual review list ** Patients who already have an adult diagnosis because they come from outside area or private <ul style="list-style-type: none"> Referrals go through triage Psychiatrist to carry out physical check rather than refer the person back to GP to enable to do the prescribing Patients is offered psychiatry appointment (after a short medical wait) for medication support and put on annual review list CAMHS transfers <ul style="list-style-type: none"> Whilst reassessment done by CAMHS, patient will first go through triage, and then Directly placed on Annual review list <div> <p><u>**Assessment to Annual review</u></p> <ul style="list-style-type: none"> Post Diagnostic Psychiatry assessment checking for suitability for medication Pre-treatment investigation based on NICE guideline (GP refers to specialist if required) Share Care form received First prescribing appointment Medication for titration session Added to annual review list Annual review appointment - frequently leads to a further period of titration. </div>	Berkshire
BHFT	Adult - autism	<p>Referrals come in from GP (via CPE) and BHFT MH services to autism first Triage</p> <ul style="list-style-type: none"> Accepted referrals that are <ul style="list-style-type: none"> prioritised are offered an appointment within 4-12 weeks Not prioritised (which form the majority) are put on a 2yr waiting list upon receiving back questionnaire (i.e. opting-in) At autism appointment, if a diagnosis is made the patient is offered 'Being me' 6 weeks psycho education course After completion of autism assessment and/or follow up the patient is discharged <p>For both Autism and ADHD Assessments, many are multidisciplinary, the patient receives feedback on the day and a comprehensive report with signposting. Priority assessment is given to those with complex mental health cases, criminal justice system, clients facing transition, if diagnosis will help with placement opportunities or university place.</p>	Berkshire

Service Gaps and issues general and under 5's

Service Category	Gaps and issues
General	<p>GP education is key with regard to the success of shared care post diagnosis for people requiring medications. Multi-disciplinary/agency way of working is not happening. Services are not evaluated on outcomes.</p> <p>The autism lead in Bracknell could be trained to deliver the Being me course.</p> <p>There needs to be better communication between organisations providing support to ensure that the persons needs and wants are aligned with their life style and activities provided for them.</p>
0-5s	<p>GPs are being asked to refer but the referral should be coming from schools and nurseries. Links with schools – more support + training, funding for school and educational psychologist required. GPs needs PEP training. Following diagnosis parents are often left without help. Autism awareness training of 4 hours is not working. There is a need for better sign posting maybe a pack at diagnosis. There is a lack of child care to enable parents to attend courses. At assessment stage there is no consultant based in Bracknell.</p> <p>Concerns over how parents are informed at this early stage. Once a concern is identified regarding a child's development it is the speed at which the process happens to address the issue that is concern. Capacity available in 3rd Sector organisation to support families at the pre and post diagnosis stages is stretched. Some pre-help from schools and nurseries needed to feed into assessment/diagnosis. Once concern is identified and referral made for early help assessment/SALT, OT paediatrician – people can get stuck at this stage for quite some time before referral made for autism assessment. Need further clarity on what support is available following diagnosis for under 5's.</p>

Service Gaps and issues 5 – 18 years

Service Category	Gaps and issues
6-18	<p>Training - Hard to access whole school training. Schools can't afford to send all staff to SHINE sessions but can't get twilight sessions booked. Twilight sessions would be much more effective if they happened than sending 1/2 staff each year.</p> <p>Pre diagnosis/Assessment - GPs are being asked to refer but the referral should be coming from schools and nurseries. Mental health professionals can screen and refer for assessment and divert to CAMHS and BHFT instead of clinical system. No access to early help support for primary schools. Whilst waiting for an early help assessment provided by local authorities (wait for assessment can be long) parents need access to support at this stage. Need to review early help assessment offer as feedback suggests people are by passing this and going straight to CAHMS and GPs which increases the waiting list for CAHMS if parent self-refers. Need a clearer protocol for referral. Is it school, GP, SENCO? Social care professionals are not asked for an opinion re autism diagnosis. Professionals question how much time clinicians spend with a child before their diagnosis. Should pre-diagnosis be change to pre-assessment? How do we address the issue that some parents want their child to be autistic as it deflects from failings as a parent. Clinicians and assessors rely only or too much on info from parents and schools who may not understand enough about autism/ADHD and don't see the child when it presents difficulties. Family information is not scrutinised plus social issues not identified. Autism awareness training of 4 hours not working. Lack of help offered when on waiting list. Lack of SALT and OT assessments and input/support for schools. Need better sign posting maybe a pack at diagnosis. Separate autism + ADHD pathways make it clunky for children, roll out joint ADHD/autism assessment following successful pilot.</p> <p>Post diagnosis - Post diagnosis maybe a need for CBT. Following diagnosis, the transition back to community services is not there. There is a gap as arrangements for education psychology, often clinicians provide consultation to families as part of feedback. Crisis support is not available, when the person reaches crisis there is a need for specialist autism/ADHD/ crisis support services. Clinicians and assessors rely only or too much on info from parents and schools who may not understand enough about autism/ADHD and don't see the child when it presents difficulties. Family information is not scrutinised plus social issues not identified. Needs for IAPT adapted for autism/ADHD, parenting workers, more child wellbeing practitioners, anxiety/autism support, ADHD workshops. Families need increased support at times of transition or difficulty. Also more capacity for ADHD ongoing review and support needed. Resource required for family support for challenging behaviour through workshops. There is a need for more tier 2 social care support for families challenged/challenging behaviour especially with more than one child with autism/ADHD and extreme behaviour. Early behaviour support would prevent crisis later. Family Support for Challenging Behaviours isn't always provided due to the high threshold. Lack of support following diagnosis. Capacity available in 3rd Sector organisation to support families at the pre and post diagnosis stages is stretched. Feedback that there is a lack in capacity for SALT and OT support.</p> <p>Once children are diagnosed there seems to be no smooth transition from community paediatrics to SALT/OT referrals. We have to apply for OT evidencing 2 terms of intervention using the CYPIT toolkit. It is very hit and miss</p> <p>There are no local inpatient services for specialised autism care, transition back to community specially commissioned beds</p> <p>Transition to adults services not consistent with feedback reporting transition poor/non-existent. Better communication/hand over required between child and adult services so families are fully supported</p> <p>There is a gap in prescribing melatonin for sleep – GPs will not prescribe and as such the child has to go back to CAMHS for an assessment and prescription.</p>

Service Gaps and issues adults

Service Category	Gaps and issues
Adults	<p>Pre-diagnosis/assessment - It is common that CMHT cannot offer mental health support for people with an autism diagnosis as they are on the autism pathway, this is not in line with NICE guidelines and should be addressed. Social care - The service level agreement between BHFT and Local Authorities only deals with LD and not autism or ADHD this means that it is difficult to case manage people with autism/ADHD as there is no support from BHFT. This needs to change.</p> <p>Not all referrals routes are well known or not used. Pre diagnosis-support does not extrapolate to adults, it does happen, in Bracknell, adult autism who then use a screening tool. The threshold for referral into the adult service is very high. Both priority and non-priority patients are sent a questionnaire. Most clients will not complete the questionnaire due to their difficulties. Big barrier! Non-priority patients are added to a waiting list (wait time 2 years) if questionnaire is returned. Great clarity is required as to how 'priority' is defined. The waiting time is considered far too long. There are no specialist autism workers within the mental health service. People often get stuck between MH and autism services. There are no arrangements for patients who get rejected after triage. There are no arrangements for patients after 'no diagnosis' at 3 hour assessment. Priority patients should get an appointment within 4-12 weeks. This is often not the case.</p> <p>Feedback from the workshops highlighted that there seems there is a threshold of 'chaos' before referrals. Medication and MH conditions sometimes interact this can cause confusion and results in patient being left without treatment. There are a lot of clients with ADHD in adult services that are unmedicated and are often in contact with criminal justice system and Mental Health Services who receive little or no support. Clients already being seen within a different service – is very difficult to get them seen/assessed. Need to think about the length of time the assessments and ADHD reviews take could be more streamlined, less wordy consider other ways of working. There is often backwards prescribing due to very limited prescribing resource/psychiatry. This is a 'pinch point'.</p> <p>Post diagnosis - Being me – 6 week course offered following diagnosis is the only outcome. Most of our clients do not find this helpful, find it overwhelming, difficult to access! Nothing further happens after diagnosis confirmed. Are people discharged? Where to? The adult ADHD team have set up a support group run by qualified volunteer – meets monthly in Reading. Feedback suggest access to this is difficult for those living in areas outside Reading. Regarding ADHD – as part of the assessment and diagnosis the person is referred to a psychiatrist who then refers the person to the GP for a physical assessment – psychiatrists are trained to carry out physical assessments (pulse and blood pressure) so this is an unnecessary step in the process causing further delay.</p> <p>Current 3rd sector support is not suitable for people who are older and have worked or have families. The support needed is different as they have often not relied on carers – more peer led support needed.</p> <p>There is scope for IAPT or similar to provide anxiety management and stress management courses adapted for small groups of people with autism and ADHD diagnosis. Also consider the possibility of adapting a mindfulness based cognitive therapy course with Talking Therapies to provide support.</p>

Appendix 5

What our stakeholders have told us

Parent survey full
Sent previously

Parent survey summary
Sent previously

autism/ADHD Project Stakeholder Questions

What services and parts of the system work well?

4 years ago, there was a large waiting list. Early support has helped reduce the waiting list. But the wait for diagnosis is still too long. Pre-diagnosis stage - people are referred to Autism Berkshire who will carry on supporting after diagnosis, even if there is no diagnosis. Training run by The Autism group. It's run by parents of children with autism. Autism group clubs run by Autism Berkshire. Advice and information provided by Autism Berkshire they give you lots of information and carry out home visits. Stand out for autism is aimed at younger children. The Windsor and Maidenhead inclusion charter was co produced and is an example of good practice. It should be considered to be rolled out across all of East Berkshire. Very good relationships with practitioners in early years. There is a post in the Windsor and Maidenhead wellbeing team who signposts parents. Once people get to CAMHS parents feel listen to. IAS services in all 3 areas support parents. The SHINE outreach team in Windsor and Maidenhead. The MAG In Windsor and Maidenhead seems to work very well for those who are pre 5 Parents experiences seamless continuity of support following diagnosis through this service why can this not be across all age groups? There is a salt drop in. At the children's centres. In Slough. They refer onto MAG. That works well. That is good communication between MAG and the schools. This is only for under fives. It is not replicated for older children. CAMHS. Has a really good website? With a Single online form to refer

What elements of autism/ADHD provision could be improved?

When parents get diagnosis, there's often no support to help reduce the child's behaviours. Behaviour modification - needs to be more robust than standard strategies. What happens when standard strategies don't work? Speech therapy is overstretched. Special schools don't do much treatment. They should work on speech, behaviour modification etc, but they don't. If you have a statement and no progress is being made, where do you go? It can be difficult when CAMHS write reports and outline what support schools should provide but then don't follow through and provide it. Parents get very frustrated. It's quite confusing sometimes. As there are 3 autism Voluntary sector providers all providing different things, some of them overlap. GP services - some are good and some GP's needs training. It would be good if we could have a named coordinator to keep you informed as to where you are on the diagnosis pathway and to hook you into services. Parents are fearful of being forgotten and falling off waiting lists. More choice with school provision. Schools that are more flexible for those with autism. Parents knowing what the local offer is. Very scattered workforce with mixed skills, including teachers in schools. Choice of educational settings is not enough. Those excluded from school this has a huge effect on their mental health, with anxiety and depression – more support is needed. Some parents don't understand what they are eligible for, some just don't have the energy to find out. There is a lack of understanding from a lot of schools. A lot of teachers don't understand autism. Post diagnosis children need support to understand themselves and how their diagnosis effects them so they can more understand themselves. There is a need for therapeutic support to manage thinking processes. There is a lack of support for parents. Those with autism don't seem to be able to access play clubs. Peer support for teenagers 9 -13 to enable them to create friendships. Greater capacity for OTs. to support TAs and training for teachers regarding sensory needs. Support is needed for siblings as they are often side-lined. Helping parents to understand how they can best support the sibling, they need space to off load. The criteria for young carers groups is too high across the whole system. Once children are in CAMHS Schools are not directly kept in the loop and should be. The choice of Schools is limited. The waiting time for diagnosis via CAMHS is too long. Parents don't understand the amount of support available in school without an ECH plan. Some schools are not as inclusive as they should be. That is no. Attachment pathway. That seems to be built in delays in cams. Probably due to process is. The CAMHS. Referral form. Online. Need. To be Flexible so referrers. Can attach? Further information. At triage. Parents are sent too much information. Which is overwhelming? CAMHS. Needs to be flexible. In accepting triage from Ed Sinek. Sensory teacher. In Slough. There seems to be a lot of paperwork and hoops to jump through. Just to get on the waiting list. And it's frustrating for parents. The information provided is difficult to understand if English is your second language.

autism/ADHD Project Stakeholder Questions cont.



What elements of autism/ADHD support are missing in the area?

Might be good to have a 12 month support worker, to enable people to access therapies and learn what to do to support behaviours post diagnosis. Social communication service needed for adults. CAMHS no longer have a clinical psychologist who would work with families at home and provide crisis support. There's a high turnover of staff in CAMHS. There is no early bird service for under a 8s in Slough. There is no early bird service under 5s in Windsor and Maidenhead. Having CAMHS located in an accessible area that isn't medicalised makes it easier for Children to attend appointments. Children often experience high anxiety when attending appointments. Having the service in a mainstream place makes it easier to manage. This would be child centred, not system orientated. More opportunities to work with young people about anxiety and understanding themselves e.g. girls in secondary school they are often self harming which is a big issue. CAMHS not always picking up the advice help line, when in crisis parents want something to take their children too. There's not enough capacity in CAMHS or therapy options. The help offered to adults via IAPT is not long not long enough adults with autism need more than 6 weeks.. The setting etc needs to be comfortable. Home support and outreach. Parent empowerment earlier on. Training on how to cope and the route to go through if you can't cope. Parents unhappiness leads to tribunals and costs local authorities. OT provision is shrinking with an 18 month waiting list. The well being of parents is central. Support needed for parents with a child at home after being excluded from school? Lack of flexibility regarding transition to meet the needs of the children. Early bird pre 5 providing outreach to preschool and Home support. When looking at a request for an ECH plan. Any behaviour is seeing us any SD or a DHD. And not attachment. We need to be able to scream for everything. The system is too rigid.

How joined up are services in your area?

There has been a big improvement in provision in the last 10 years. Clinicians talk to each other and are able to address issues but there is no joined up thinking across the system in East Berkshire at the moment. CAMHS move to Upton Hospital has meant that services are more disjointed. Due to loss of staff those who were seeing a psychologist prior to the move to Upton hospital. Some of them are now on a waiting list, as there is no psychologist to treat them, some of them have been waiting since October last year. It seems that there is a lot of argument over budgets. Is there an argument for pool budget for autism and autism? Schools and health are not joined up. Salt is not in schools. Unclear about the role of health visitors and school nurses. There is no link between ISS and comes. Advisory teacher's linking between children and adults. Is not joined up as it should be? CAMHS. Don't see children in their natural environment as part of the assessment. This must affect the assessment. Education and health a separate. The early intervention. Available prior to the medical pathway is not understood by health. We need a person centred approach.

How do services and stakeholders communicate?

Parents are finding their own pathway. There are partnership boards run by local authorities but only for adults. Bracknell no longer runs theirs's. There is the transforming adults board, but no formal provider forum. Communication across all organisations needs to improve. The consultation regarding Nicolson's Walk was not widely known. Both to see CCGs and local authorities needs to use more user friendly language. Parents find out more from each other. We need to stop labelling people who are waiting to see a psychologist, children are describing themselves as having autism whilst still waiting for a diagnosis. Communication is dependent on individual relationships. Parents hear about training from SENCOs. Often schools wait until diagnosis to put in an application for an ECH. Plan but they don't need to wait for the diagnosis, as its according to need. There is no forum to communicate. SALT and OTs are keen to pull their services together to prevent overlap. There are regular SENCO meetings. There is the children's transformation board but that's at a strategic level. We Need better communication. At a practitioner level.

autism/ADHD Project Stakeholder Questions cont.

How are people diagnosed in your area? How can that be improved?

People are waiting 2 years to be diagnosed. There is quicker a assessment for children under fives. There is a nursing group assessment in the Royal Borough of Windsor but the diagnosis letters need to be clearer. Parents are constantly checking whether their child is on the waiting list, this must take a lot of time from CAMHS to respond, taking resources from elsewhere. There is no single pathway for ADHD and autism. You can go on the autism pathway and receive a diagnosis for autism and then have to go on a another pathway for an ADHD assessment. This could take another 2 years. It would be good if there was one pathway that screamed for all associated autism conditions all at the same time rather than asking people to go on separate waiting lists. Young children receive a multi-agency assessment. Those who are older go through CAMHS. Those who can afford it go through the private route. More capacity across all services. One door for screening for everything. Consider ways of accessing therapy for those who are house or room bound? E.g. home visits/Virtual visit. Supported accommodation specially for those with autism. Needs planning in advance and floating support. There is a bottle neck between under 5's assessment and CAMHS.

How are services evaluated? How do you know if a services is effective?

We send our performance report to the CCG. We use the friends and families test. Quality management is an issue. How do we know when the service is good? Find activity data to the CCG but it is not outcome focused. Services are not evaluated is difficult to know whether a services affective or not. It is unclear as to what outcomes the system is looking for.

Are there any training gaps across autism/ADHD provision in the area?

More training in schools for staff needs to be done by educationalists as teachers don't listen to none educationalists. We have provided training to Reading Buses maybe we could do something similar In East Berkshire. We've trained 150 nurses in Wexham Park. There is a need for training for GPs, dentists and orthodontist's. Autism awareness training is in need for. Family training in challenging behaviour. We need a socialising course for adults with autism. The autism group offer parents training and support as do parenting special children. There is a need for autism training across all professions, including any frontline services. There is an awareness, but they don't understand it, everyone is different. Schools don't have the budget to release staff for training. Schools understanding - awareness training. Training for early years. Should be more online training that is mandatory. TAs would be able to access this training. IAPT staff need to be trained in autism. Training is difficult for parents because of the timings of when the training is organised. Medical professionals need training across multiple areas: OCD, attachment, mental health. It is not linear especially workforce development - training needs to be wholistic. Building peoples confidence to support children in people with multiple me. Whole school training. Headteachers. It needs to be everyone's business. Conflict resolution training. Stop and assess. Tier 2.5 gaps training and skill development for staff- how young people may present when distressed or anxious. Needs based support training at the point of diagnosis – intensive behaviour analysis. Nothing around ADHD – how they may express.

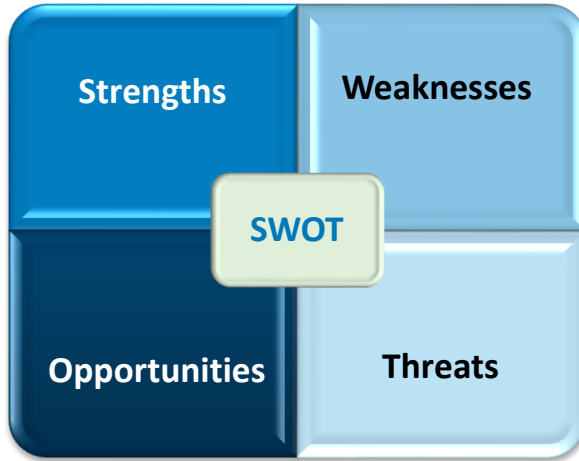
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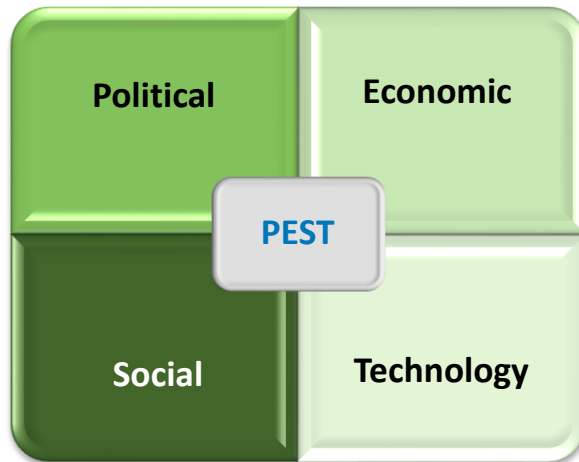
Appendix 6 Market analysis supporting information

SWOT / PEST Analysis

In order to aid our analysis we have utilised two tools:



A SWOT analysis is a structured planning method that evaluates four elements. It involves specifying the objectives of services and identifies the internal and external factors that are favourable and unfavourable to achieve that objective.



A PEST analysis uses a framework of macro-environmental factors used in strategic management. When conducting strategic analysis or doing market research, it provides an overview of the different factors to be taken into consideration.

It is a strategic tool for understanding market growth or decline, potential and direction for services.

SWOT analysis of the current market in East Berkshire

Strengths

- › Willingness for stakeholders to work together to improve services
- › A East Berkshire/wide/ICS service model could be in scope for future commissioning and provision
- › Willingness of clinicians to collaborate to improve outcomes
- › Evidence of clinical skill and compassion
- › Good links with Local Authority/CCG requirements
- › Third sector services willing to work together
- › Developing workforce e.g. Child wellbeing and family practitioners

Opportunities

- › To move towards more personalised care (including more community-led service provision) / Personalised Health Budgets to be explored
- › Shift towards outcomes focused services and quality premiums
- › The market is responding to a BE needs but more development is needed
- › A less medicalised service model
- › An appropriate balance between cooperation and contestability will allow stability alongside some new organisations (i.e. GP Federations)
- › Implement an outcomes focused pricing model
- › Introduction of detailed specifications and innovative contracts
- › Better links between Local Authorities/CCG requirements, cross sector procurement opportunity

Weaknesses

- › Lack experience of providing integrated services for ADHD/autism (NICE compliant services), therefore, risk to services/complaints
- › Further engagement required with patients, family, carers, GPs and voluntary sector
- › Greater understanding of providers is needed by commissioners. This includes outcomes metrics, current pathways, benchmarking between providers
- › Capacity of the incumbent service providers is very limited
- › Quality of data could be improved
- › East Berkshire may not be seen as attractive to the market because of costs and logistics to deliver in a small geographical environment
- › Health & wellbeing strategic links are well established, skills however are not yet well deployed in the broader community
- › There are fragmented services however this also provides opportunities & threats
- › There are no clear commissioning intentions for these services

Threats

- › Recruitment and retention (e.g. SALT/occupational therapists) – although this could also be an opportunity to create new roles
- › Political uncertainties in relation to policy on competition, public sector financial challenges
- › Requirements could strip current capacity leading to increased costs
- › Competition requirements need careful approaches in East Berkshire as there is a risk of destabilising current providers
- › Private providers recognise a good commercial opportunity in providing these services
- › Provider collaboration / working together cohesively

Summary: The Market is led by the local acute provider with a few third sector organisations providing support to families and people with autism and or ADHD. Current providers are keen to further develop their business and few providers are interested in entering the market. A collective strategy towards collaboration across health and social care could be developed to manage the market and leverage better value for money.

PEST analysis of the current market in East Berkshire

Political

- › NICE guidelines for these services
- › Changing political landscape, competition vs. integration
- › Care closer to home, less reliance on hospital based services wrapping care around the person
- › Changes to quality regulation and compliance and establishment of Care Quality Commission
- › Expectation that outcomes improve and become amongst the best in Europe
- › Significant reduction in health inequalities and changed role for NHS in reducing the current gap
- › Transforming Care
- › Ongoing governance and decision making arrangements (where does the decision to commission autism/ADHD services take place?)

Economic

- › Lack of clarity of current costs of the services provided by the Trust due to block contract
- › Lack of clarity of current costs of Third Sector services due to multiple commissioners
- › Annual challenge to offset uplifts becomes the norm, market will need to focus on efficiency / continuous improvement
- › Global economic downturn and period of significant UK austerity - costs need to be controlled
- › Constrained funding to NHS and other public sector bodies with whom we work closely
- › Providers have restricted access to capital and borrowing

Social

- › Peoples health and well being is paramount
- › Care closer to home and care around the person are key objectives
- › Greater national recognition of mental health, parity of esteem
- › Growing patient/carer expectation of both the quality and experience of care
- › A more health literate public driving both demands and concerns about healthcare
- › Diverse deprivation profile and resulting impacts on health of local population

Technology

- › IT system integration (BHFT/GPs/LAs/3rd Sector)
- › On line assessment
- › SHaRON
- › More access to virtual consultations (via Skype)
- › Advancements in technology leading to new practice and improved life expectancy
- › Pharmaceutical progress and reliance upon NHS for adoption and spread
- › IM&T System development and requirements
- › More use of E learning

Summary: Financial pressures combined with the move towards integration will drive change, focusing on the development of wrapping care around the person from the acute through to the community, including schools, and family/carers/partners. This will drive growth of the community services market. Are commissioners gearing up for this?

Current market performance:

Review	Current Status & Issues	Score (1-5)
Competition	The ADHD/autism services landscape indicates that whilst the commissioning of services is fragment the number of providers providing services is limited with BHFT as the dominant provider, accounting for the majority of the spend. Additional provision may be available either by direct commissioning by CCG/LAs or via a subcontracting arrangement by BHFT. This however is dependant on the availability of independent and 3rd sector provision and funding.	3
Access	Access to the provision of autism and ADHD in children's and adults services is limited. Due to the nature of the problem, the increasing numbers of people being referred into the services and the rate of clearing people from backlogs and through treatment and diagnosis pathways, the problem of access is an increasing one. This results in a lack of flexibility in terms of personalised care.	5
Quality & Outcomes	All providers should look to determine clear outcomes for each individual within their services, and agree with the commissioner the approach to measuring and reporting on outcomes	5
Patient Choice	Due to the limited availability of providers offering the services, as well as geographical limitations, once within a service, individuals may be offered a range of options in relation to their treatment and recreational activities however there is no consistency.	4
Value for Money	Providers state that they "provide value for money", however, this needs to be considered against the cost of a higher impact/focused delivery model more in line with the demand level being experienced across England.	3
		20 / 25

Note:
Score (1 – Good (impact on market performance) 5 – Relatively Bad (Impact on market performance - High Need to Improve)

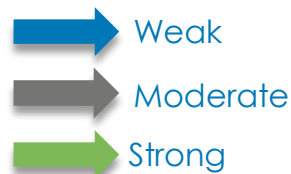
Porters Analysis

The porters analysis supports the service summary observations:

- A need for joint commissioning of services
- Greater integration across service provision

These two elements may shift the market forces from weak to medium thereby creating the opportunity for service transformation.

Relative Strength Of The Threat



Supplier Power: 4

Experienced in providing community paediatric services but lacks integration. There is not a strong track record of collaborating with other supply chain partners (such as, GP Federations)

Government: 7

Government standards, registration requirements as well as policy to increase parity of esteem adds to the pressure on the market place

Threats of new entrants: 1

The threat of new entrants is low. The complex set of service provision and relatively low margins do not make this an attractive market for many independent providers

Industry Rivalry: 4

Relative weak competitive pressure given:-

- Few number of providers
- Lack of market leading independent providers
- Historic market growth

Threat of Product Substitution: 7

Different services such as, schools, family/carer support will have some barriers to overcome such as regulation, shortage of appropriate workforce and cost

Buying Power: 7

Threat from commissioners is potentially strong. They do not however lever this appropriately and to date has not operated as a clear commissioning entity across Health & Social Care. Clarity of Joint commissioning arrangements with Local authorities would strengthen this leverage

<4	4 to 7	>7
weak market forces	medium market forces	strong market forces

Market analysis - Buckinghamshire

Organisation	Category	Summary of service
GRASPS Autism Support Group	Children, Young People, Adults & Families	<p>Greater Resources for Autism Supporting Parents and Siblings (Established: March 2013)</p> <p>GRASPS is voluntary run, inclusive support group for families, young adults and adults, affected by Autism in Buckinghamshire.</p> <p>As of July 2017 they will only authorise new members who live in Buckinghamshire and the adjoining counties, as their joint knowledge and SEND information is relevant to Buckinghamshire policy and procedure.</p> <p>There is a private Facebook support forum for, families, adults and teens directly affected by autism. GRASP aim to be as inclusive as possible.</p> <p>GRASP hold monthly daytime and evening support meetings in Aylesbury and South Bucks with the primary objectives of sharing and exchanging information; providing essential empathy, support, acceptance and understanding for one another.</p>
Buckinghamshire Adult Autism Diagnostic Service (Oxford Health NHS Foundation trust)	Adults	<p>Referral service for GPs to request autism assessment/diagnosis. Request may be made for supporting information from GPs as well as questionnaires to complete (including ADOS forms) to support the diagnostic process.</p>
CAMHS - Oxford Health NHS Foundation trust	Children, Young People, & Families	<p>CAMHS support a variety of children and young people from 0 to 18 years old with different needs.</p> <p>This ranges from moderate anxiety, to depression and eating disorders. CAMHS consists of different teams which include:</p> <p>Community CAMHS CAMHS Outreach Service (OSCA) Neuropsychiatry Service Learning Disabilities CAMHS services for high risk young people</p>

Market analysis – Buckinghamshire cont..

Organisation	Category	Summary of service
FACT Bucks	Children, young people & families	Families and Carers Together in Buckinghamshire, is a group of parents and professionals who meet to discuss real issues that affect children and young people with additional needs and disabilities in Buckinghamshire.
National Autistic Society	Families	There are 3 NAS branches across Buckinghamshire which have been set up and run by parents. These groups vary in size and what they offer, which can include practical information and advice, friendship, emotional and moral support and activities for the family.
Various	Children, Young People, Adults & Families	Listed in the local offer there are 8 other voluntary sector groups & providers across Buckinghamshire, based in the voluntary sector, which offer services to support families, children, young people & adults

Market analysis - Hillingdon

Organisation	Category	Summary of service
Hillingdon CAMHS (Central & North West London NHS Foundation Trust)	Children, Young People & Families	<p>Hillingdon CAMHS provides community mental health services to children, young people up the age of 18, with complex mental health difficulties, and their families in a range of different ways depending on their needs.</p> <p>Their psychologists, psychiatrists, and therapists provide assessment and treatment packages for children, young people and their families. Treatment may include cognitive behavioural therapy (CBT), family therapy, play therapy, individual and group psychotherapy. Medication is also used when appropriate and carefully monitored by the doctors.</p>
CAAS (Centre for autism & Autism Support)	Children, Young People & Families	<p>The Centre for ADHD and Autism Support (CAAS) supports educates and empowers individuals with ADHD and/or on the autism spectrum, their families and the community. Through raising awareness, they change perceptions and break down barriers. They offer a wide range of support services to families across NW London, including, training, drop in sessions, workshops, 1-2-1 support, outreach services, therapy & support groups</p>
HACS (Hillingdon Autistic Care & Support)	Children, Young People, Adults & Families	<p>HACS is local charity based in the London borough of Hillingdon for children and young people on the autism spectrum. Through provision of high-quality Family Support, Training, Recreation Services and Employability services the aim of the charity is to minimise disability and maximise ability of autistic individuals. They strive to improve quality of life for autistic children, adults and their families through continued efforts to raise awareness of autism, campaigning for appropriate support at local and national level and by promoting inclusion in universal services.</p> <p>HACS keep individuals on the autism spectrum and their parents and carers informed of the most up-to-date information, through our quarterly newsletter, e-bulletins and access to an ever-expanding resource library.</p> <p>HACS provide a voice for the autism community in Hillingdon to influence service development and delivery through our partnership working with the Local Authority, to address health disadvantages for individuals on the autism spectrum.</p>
Attention Hillingdon	Children, Young People & Families	<p>Attention Hillingdon is an exciting and innovative project currently running with over 80 nurseries, playgroups and children's centres within the borough. The intervention supports the development of attention and listening skills, and promotes the development of social communication skills.</p>

Market analysis – Hillingdon cont..

Organisation	Category	Summary of service
Hillingdon SENDIASS	Children, Young People & Families (including 16-25 yrs)	<p>This Service provides information, advice and support for parents of children and young people with SEN or disabilities, about education, health and social care. The Service provides legally based, impartial, confidential and accessible information, advice and support and will be able to offer face to face, telephone advice as well as casework and representation when needed.</p> <p>They offer support to parents of children with special educational needs and those who have been excluded or are at risk of being excluded from school. The Service will often work with parents and children/young people together but will also provide a service directly and separately to young people aged 16-25.</p> <p>The service encourages partnership between parents, LA's, schools and voluntary bodies with the work of identifying, assessing and making provision for children and young people with SEN.</p>
DASH (Disablement Association Hillingdon)	Children, Young People, Adults & Families	<p>Disablement Association Hillingdon known more commonly as DASH, was formed in 1984 and is a user-led charity based in Hillingdon, West London. DASH challenges people's perceptions and encourages disabled people of all ages to reach their full potential.</p>

Market analysis - Wokingham

Organisation	Category	Summary of service
Assist	Children, Young People & Families	<p>Wokingham Borough Council support team, known as ASSIST, works with parents and practitioners to support children and young people across the autism spectrum.</p> <p>The ASSIST team (Autism Spectrum Service for Information, Support & Training) is part of the 0-25 Special Educational Needs and Disability Service at Wokingham Borough Council People's Directorate, based at Woodley Airfield Centre.</p> <p>The team supports children and young people with autism, people who live with them, and people who work with them from diagnosis up to their 18th birthday, and who live in the Wokingham Borough. The service can provide:</p> <ul style="list-style-type: none"> • Information, support, advice and signposting to other services • Resources such as symbols, photographs and timetables • Opportunities to meet with the ASSIST team to discuss strategies – contact the team for dates of monthly drop in sessions held at Bridges Resource Centre • Support to families to look at issues in the home environment and move towards solutions • Support to school staff to look at issues in the school environment and move towards solutions • Support to leisure providers to include children with autism • Consultation support to professionals to look at issues and solutions • Co-ordination of NAS EarlyBird, EarlyBird plus and Healthy Minds parent programmes, and the Next Steps parent programme • National Autistic Society EarlyBird, EarlyBird Plus and Healthy Minds parent programmes (overseen by NAS and managed locally by the ASSIST team)
CAMHS – Berkshire Healthcare NHS Foundation Trust	Children, Young People & Families	<p>The children and adolescent mental health service (CAMHS) works with young people who are experiencing significant, severe and complex difficulties with their mental health.</p> <p>These difficulties range from feeling low a lot of the time and worrying about lots of things to finding and fitting in with friends, hearing voices, having significant difficulties around eating, self-harming and even considering killing themselves.</p>

Market analysis – Wokingham cont..

Organisation	Category	Summary of service
Hoffman Foundation for Autism	Children, Young People & Families	Hoffmann Foundation for Autism is a registered charity now celebrating its sixtieth year of providing a range of specialist services to adults with an Autism Spectrum Condition. We ensure that the people we support receive an individualised service, which will assist them in living a life that is more meaningful to them.
Various	Children, Young People, Adults & Families	Listed in the local offer there are 20 other voluntary sector groups & providers across Wokingham that offer support for children, young people, adults & families with autism/ADHD

Market analysis – Oxfordshire

Organisation	Category	Summary of service
Oxford ADHD & Autism Centre	Children, Young People, Adults & Families	<p>Oxford ADHD & Autism Centre is the first specialist independent clinic in Oxford for children and adults with ADHD, autism and related conditions, such as specific learning difficulties, anxiety and depression. The centre is able to offer assessments and also ongoing management and follow-up, including treatment with medication if appropriate. They have specialist ADHD and autism coaches working within the Oxford ADHD & Autism Centre, and Support Groups for adults and parents/carers.</p> <p>The service also understands the difficulties faced by patients during the transition from adolescence to adulthood, which is often a time when young people are transferred to different services and continuity of care may be lost. At the Oxford ADHD & Autism Centre they are able to ensure this continuity by offering a lifespan service.</p>
CAMHS - Oxford Health NHS Foundation trust	Children, Young People, & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. We value the role of the family in the recovery process and where possible family support is an integral part of their work.</p> <p>Anyone can make a referral. The service wants this to be as easy as possible for people. Referrals can be completed via the website using the self-referral form</p>
Autism Oxford UK Ltd (Oxfordshire County Council)	Children, Young People, Adults & Families	<p>Autism Oxford raises awareness of the realities of life on the autism spectrum and supports the development of autism services. They offer training sessions and speaker events featuring people on the autism spectrum, family members and expert professionals in the field.</p> <p>Autism Oxford provides Oxfordshire's first Autism Alert Card Scheme, which offers a card free to anyone on the Autism Spectrum in Oxfordshire.</p> <p>For adults with an Oxfordshire GP who are seeking an autism spectrum diagnostic assessment, Autism Oxford provides a pre-assessment discussion and referral service. This service is free (funded by the NHS) for people who do not have a Learning Disability or a service from Mental Health teams. To access this service, people ask their GP for a referral to Autism Oxford.</p>

Market analysis – Oxfordshire cont..

Organisation	Category	Summary of service
OASIS	Children, Young People, & Families	<p>OASIS offers information and support to parents and carers of children with autistic spectrum disorders</p> <p>OASIS are a friendly charity run by parent volunteers for those bringing up children and young adults on the Autistic Spectrum. They welcome all parents, carers and individuals and can cater for all aspects of the spectrum, this includes classic Autism, Asperger's Syndrome and other related conditions such as Sensory Processing Disorder, Fragile X and Developmental Delay.</p> <p>OASIS aims to create a supportive community through family events, informal coffee and chat groups, evening speaker meetings and subsidised playdays which run all over the county.</p>
Various	Children, Young People, Adults & Families	Listed in the local offer there are 14 other voluntary sector groups & providers across Oxfordshire that offer support for children, young people, adults & families with autism/ADHD

Market analysis - Reading

Organisation	Category	Summary of service
Autism Berkshire	Children, Young People, Adults & Families	<p>Autism Berkshire was founded as the Berkshire Autistic Society in 1990 by a group of parents of children with autism, related conditions and challenging behaviours.</p> <p>Today they are the leading autism charity in Berkshire and deliver quality specialist services, training and social and leisure activities throughout the county, guided by a team of trustees with personal and professional experience of autism. Their mission is to help and support anyone living with autism in Berkshire. They aim to enhance the current provision of services and support, with the purpose of improving the quality of life of people with autism and giving them maximum independence.</p> <p>The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals.</p> <p>Services include:</p> <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers
CAMHS – Berkshire NHS Foundation Trust	Children, Young People & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. CAMHS value the role of the family in the recovery process and where possible family support is an integral part of their work.</p> <p>Anyone can make a referral. They want this to be as easy as possible for people. These can be completed via the website using the self-referral</p>

Market analysis – Reading cont..

Organisation	Category	Summary of service
Centre for Autism (University of Reading)	Children, Young People, Adults & Families	<p>The Centre for Autism is a regional hub for research and training in autism, located within the University of Reading.</p> <p>Research at the Centre uses a range of neuroscience techniques to examine core features of autism and to support the development of clinical interventions. All work is disseminated widely to the public as well as to a network for health and education professionals, through regular lectures, workshops and special interest group meetings.</p> <p>To support their research they also offer adult and student diagnostic services and intervention where appropriate.</p>
Dimensions	Children, Young People, Adults & Families	<p>Dimensions support people who have a wide range of learning disabilities and autism to live the life they choose, gain increased independence and achieve their goals and ambitions. They are experts in communicating with those who find it hard to be heard. Staff listen to what people and their families tell them. Dimensions successfully support people with even the most complex needs and challenging histories to be part of their community, enabling them to have greater choice and control, and to live an ordinary life.</p>
Creative Support Reading	Children, Young People, Adults & Families	<p>Creative Support is a not-for-profit organisation with 20 years experience of offering person centred support to people with learning disabilities, mental health and other support needs.</p> <p>The service promotes the independence, inclusion and well being of people with support needs. They do this by working with the people they support, their families and partner agencies to deliver innovative, high quality services that meet their needs and aspirations.</p> <p>The service works with people with a wide spectrum of needs, ranging from those who require short term support to regain their independence to people with complex needs requiring intensive support to enjoy a good quality of life.</p> <p>All their services are individualised, person centred and deliver valued outcomes, they passionately believe that their service users have the right of choice and to live lives that are meaningful and which enable them to reach their full potential as individuals.</p>
Various	Children, Young People, Adults & Families	<p>Listed in the local offer there are 20 other voluntary sector groups & providers across Reading that offer support for children, young people, adults & families with autism/ADHD</p>

Market analysis – West Berkshire

Organisation	Category	Summary of service
Autism Berkshire	Children, Young People, Adults & Families	<p>Autism Berkshire was founded as the Berkshire Autistic Society in 1990 by a group of parents of children with autism, related conditions and challenging behaviours.</p> <p>Today they are the leading autism charity in Berkshire and deliver quality specialist services, training and social and leisure activities throughout the county, guided by a team of trustees with personal and professional experience of autism. Their mission is to help and support anyone living with autism in Berkshire. They aim to enhance the current provision of services and support, with the purpose of improving the quality of life of people with autism and giving them maximum independence.</p> <p>The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals.</p> <p>Services include:</p> <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers
CAMHS – Berkshire Health NHS Foundation Trust	Children, Young People & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. CAMHS value the role of the family in the recovery process and where possible family support is an integral part of our work.</p> <p>Anyone can make a referral. They want this to be as easy as possible for people. These can be completed via the website using the self-referral</p>
Various	Children, Young People, Adults & Families	<p>Listed in the local offer there are 8 other voluntary sector groups & providers across West Berkshire that offer support for children, young people, adults & families with autism/ADHD</p>

Market analysis – Bracknell Forest

Organisation	Category	Summary of service
Autism Berkshire providing services across all of Berkshire	Children, Young People, Adults & Families	<p>Autism Berkshire was founded as the Berkshire Autistic Society in 1990 by a group of parents of children with autism, related conditions and challenging behaviours.</p> <p>Today they are the leading autism charity in Berkshire and deliver quality specialist services, training and social and leisure activities throughout the county, guided by a team of trustees with personal and professional experience of autism. Their mission is to help and support anyone living with autism in Berkshire. They aim to enhance the current provision of services and support, with the purpose of improving the quality of life of people with autism and giving them maximum independence. The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals. Services include:</p> <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers
CAMHS – Berkshire Health NHS Foundation Trust	Children, Young People & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. CAMHS value the role of the family in the recovery process and where possible family support is an integral part of our work.</p> <p>Anyone can make a referral. They want this to be as easy as possible for people. These can be completed via the website using the self-referral</p>

Market analysis – Bracknell Forest cont..

Organisation	Category	Summary of service
Parenting Special Children providing services in Bracknell, Slough and Windsor and Maidenhead	Parents & Carers	PSC run various courses and workshops & Parenting Programmes throughout the year, such as: <ul style="list-style-type: none">- Pre & Post Autism Workshops- Pre & Post ADHD Workshops- Time Out for ADHD- Time Out for Autism- Anxiety & Autism Workshop- Sleep Workshops- Pre & Post Diagnosis Support- Looked After and Adopted Children with Special Needs- Time out for Special Needs- Parenting Support- Bespoke Training- Autism Girls Monthly Speaker Events
Various	Children, Young People, Adults & Families	Listed in the local offer there are 23 other voluntary sector groups & providers across Bracknell Forest that offer support for children, young people, adults & families with autism/ADHD

Market analysis – Slough

Organisation	Category	Summary of service
Autism Berkshire	Children and adults	<p>Autism Berkshire was founded as the Berkshire Autistic Society in 1990 by a group of parents of children with autism, related conditions and challenging behaviours.</p> <p>Today they are the leading autism charity in Berkshire and deliver quality specialist services, training and social and leisure activities throughout the county, guided by a team of trustees with personal and professional experience of autism. Their mission is to help and support anyone living with autism in Berkshire. They aim to enhance the current provision of services and support, with the purpose of improving the quality of life of people with autism and giving them maximum independence.</p> <p>The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals. Services include:</p> <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers
CAMHS – Berkshire Health NHS Foundation Trust	Children, Young People & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. CAMHS value the role of the family in the recovery process and where possible family support is an integral part of our work.</p> <p>Anyone can make a referral. They want this to be as easy as possible for people. These can be completed via the website using the self-referral</p>

Market analysis – Slough cont..

Organisation	Category	Summary of service
ADHD Team – Berkshire Health NHS Foundation Trust (Service provided as part of CAMHS across East Berkshire)	Children, Young People & Families	<p>The service offers an experienced multi-disciplinary team who assess and provide treatment for young people between the ages of 6 and 18 who are suspected of having, or who have been diagnosed with, attention deficit hyperactivity disorder (ADHD).</p> <p>The team comprises consultant psychiatrists, staff grade psychiatrists, clinical nurse specialists, non-medical prescribers and assistant psychologists</p>
Home Start Family Support Service	Parents & Carers	Home start are the biggest local voluntary organisation to recruit and train volunteers to provide support and a listening ear to struggling families with children under five.
Various	Children, Young People, Adults & Families	Listed in the local offer there are 70 other voluntary sector groups across Slough that offer support for children, young people, adults & families with autism/ADHD

Market analysis – Windsor & Maidenhead

Organisation	Category	Summary of service
Autism Berkshire providing services across all of Berkshire	Children, Young People, Adults & Families	<p>Autism Berkshire was founded as the Berkshire Autistic Society in 1990 by a group of parents of children with autism, related conditions and challenging behaviours.</p> <p>Today they are the leading autism charity in Berkshire and deliver quality specialist services, training and social and leisure activities throughout the county, guided by a team of trustees with personal and professional experience of autism. Their mission is to help and support anyone living with autism in Berkshire. They aim to enhance the current provision of services and support, with the purpose of improving the quality of life of people with autism and giving them maximum independence.</p> <p>The main aims of the charity are to provide a comprehensive advice and information service for parents, carers and professionals. Services include:</p> <ul style="list-style-type: none"> - Autism Alert Card - Autism Friendly Film Screenings - Benefits Service - Bracknell Adult Social Group - CAYP Youth Group - Family Swimming - Lego Club - Parents and Carers Support Group - Trampolining - Workshops for Parents and Carers
CAMHS – Berkshire Health NHS Foundation Trust	Children, Young People & Families	<p>Children and young people who have mental health needs will receive timely and evidence based interventions in a caring, compassionate and non-judgemental environment. CAMHS value the role of the family in the recovery process and where possible family support is an integral part of our work.</p> <p>Anyone can make a referral. They want this to be as easy as possible for people. These can be completed via the website using the self-referral</p>

Market analysis – Windsor & Maidenhead

Organisation	Category	Summary of service
Achieving for Children	Children, Young People & Families	<p>Youth Centres are a mainstream service that everyone can access including young people with additional needs. People can discuss their particular needs and any support requirements with the session leader. Young people are also welcome to bring a Support Worker/Carer.</p> <ul style="list-style-type: none"> - 4 Marlow Road Youth Centre - Esteem Project - Windsor - Esteem Project - Maidenhead - Eton Wick Youth Centre - Larchfield Children's Centre - Manor Youth Centre - Pinkneys Green Youth Centre
The Autism Group Providing services in Bracknell, Slough and Windsor and Maidenhead	Children, Young People & Families & Carers	<p>The Autism Group offers free Parent Support and Social groups, parent training sessions and a home visit service for residents in the Boroughs of Windsor and Maidenhead, Slough and Bracknell. These services are offered to parents of children and young people of any age who either have a diagnosis of an autism spectrum condition or are on the diagnosis pathway awaiting assessment</p>
Various	Children, Young People, Adults & Families	<p>Listed in the local offer there are 26 other voluntary sector groups & providers across Windsor & Maidenhead that offer support for children, young people, adults & families with autism/ADHD</p>

Market Analysis - Hampshire

Organisation	Category	Summary of service
Surrey and Borders Partnership NHS Foundation Trust – Hampshire	Autism Service - Adults	<p>The Hampshire Autism Service provides their well established model of diagnosis and support for adults with Autistic Spectrum Disorders.</p> <p>Once referred for an autism assessment a specialist practitioner will review the details and, if appropriate, add the person to the waiting list within two weeks.</p> <p>People will be sent a letter six weeks before an appointment which will contain several self-completion tests including: AQ; EQ; SCQ; a short sensory profile, and two gathering information tools. These tests will be used by the practitioner during the appointment to make an initial assessment and to produce a diagnostic report which will be discussed with the consultant.</p> <ul style="list-style-type: none"> •AQ: This test helps to measure the extent of autistic traits in adults •EQ: This questionnaire helps to measure empathy in adults •SCQ: This test provides routine screening for Autistic Spectrum Disorders. <p>If the diagnosis is clear, an immediate referral is made to their partner, Autism Hampshire, and a copy of the person's diagnosis report is sent to them. They will offer a follow up appointment within 90 days to discuss support options. If the person decides not to attend this appointment a diagnostic report detailing a range of strategies will be sent to them and any onward referrals will copied to their GP.</p> <p>If the diagnosis is unclear or complex a multi-disciplinary team will review the assessments and agree on a treatment path or signpost the person to other services.</p> <p>Autism Hampshire provides non-clinical pre and post diagnostic support including:</p> <p>One-to-one individual support</p> <p>Support is based on individual need and is offered pre, during, and post diagnosis. It consists of developing support plans, goal setting, and signposting.</p> <p>Post diagnosis support</p> <p>A post diagnosis follow-up meeting is offered to allow the person the opportunity to discuss their individual support plans. Autism Hampshire will use the diagnosis report and recommendations made by Surrey and Borders Partnership clinicians to discuss the implications of the diagnosis, and the support available.</p> <p>Drop in sessions</p> <p>Support, information and networking opportunities are available through regular drop in sessions.</p> <p>Telephone information line</p>

Market Analysis - Hampshire

Organisation	Category	Summary of service
Mindsight Surrey CAMHS - Surrey and Borders Partnership NHS Foundation Trust, Xenzone, Surrey Family Services, the National Autistic Society, Barnardo's, Relate West Surrey, Step by Step, Heads Together, Brain in Hand, Eikon, and Learning Space	Autism and ADHD assessment - children	<p>Mindsight Surrey CAMHS is a partnership of expert organisations including Xenzone, Surrey Family Services, the National Autistic Society, Barnardo's, Relate West Surrey, Step by Step, Heads Together, Brain in Hand, Eikon, and Learning Space.</p> <p>This service is responsible for providing all follow up appointments for children and young people who have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (autism).</p> <p>Areas Covered</p> <ul style="list-style-type: none"> •Runnymede •Spelthorne •Woking <p>Referral Process</p> <p>The service only accept referrals from health, social care and education professionals.</p> <p>Their wide range of dynamic, high performing partners are working with them to deliver greater support to more children and young people with the aim of reaching them before they become very unwell.</p> <p>Through a single point of referral, they offer a 'no wrong door' approach, providing support to children, young people and families to find the right help at the right time.</p> <p>Services for children and young people</p> <p>they provide help and support to children and young people when they begin to feel emotionally or mentally unwell to build wellbeing and resilience to reduce the chances of their condition becoming more serious.</p> <p>Together with their partners they deliver targeted and specialist services, connecting with universal services to ensure support is available at entry level, from primary mental health in schools through to urgent needs.</p> <p>Service Description</p> <p>This service is responsible for providing all follow up appointments for children and young people who have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (autism).</p> <p>Areas Covered</p> <ul style="list-style-type: none"> •Runnymede •Spelthorne •Woking <p>Referral Process</p> <p>They only accept referrals from health, social care and education professionals.</p>

Market analysis - Hampshire

Organisation	Category	Summary of service
Autism Hampshire	Various services for all ages	<p>Autism Hampshire provides non-clinical pre and post diagnostic support including: One-to-one individual support. Support is based on individual need and is offered pre, during, and post diagnosis. It consists of developing support plans, goal setting, and signposting. Post diagnosis support. A post diagnosis follow-up meeting is offered to allow the opportunity to discuss the individual support plans. Autism Hampshire will use the diagnosis report and recommendations made by Surrey and Borders Partnership clinicians to discuss the implications of the diagnosis, and the support available. Drop in sessions Support, information and networking opportunities are available through regular drop in sessions. Through their understanding of autism and the impact it has on the individual, we work with people to help them develop skills and strategies to gain greater control over their lives.</p> <p>Services provided include: Advice and information, services for parents and carers, training and consultancy, information for professionals, specialist mentoring services, housing and support services.</p>

Market analysis - Surrey

Organisation	Category	Summary of service
Surrey and Borders Partnership NHS Foundation Trust – Surrey	Autism and ADHD service - Adults	<p>The autism and ADHD Service for Surrey provides diagnosis and support for adults with Autistic Spectrum Disorder (autism) and Attention Deficit Hyperactivity Disorder (ADHD) across Surrey. Their model of diagnosis and care is well established and refines the proposals made in the 2011 Autism Act.</p> <p>Areas Covered</p> <ul style="list-style-type: none"> • Elmbridge • Epsom and Ewell • Guildford • Mole Valley • Reigate and Banstead • Runnymede • Spelthorne • Surrey Heath • Tandridge • Waverley • Woking <p>Referral Process</p> <p>Referrals to the service are only accepted from health and social care professionals, including community mental health teams, GPs, and adult social care.</p>

Market analysis - Surrey

Organisation	Category	Summary of service
The Asperger's & Autism Clinic	Asperger's and autism assessment	<p>A specialist team at Hampshire & Surrey Psychology who are fully qualified to assess and diagnose Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder. Additionally, regardless of whether or not a diagnosis is given, we offer psychological therapy for individuals and families affected by these conditions.</p> <p>They are able to provide a high quality assessment, counselling and therapy services for people diagnosed with an Autism Spectrum Disorder or Attention-Deficit Hyperactivity Disorder (ADHD) and their families, to aid in making day to day living easier. They work in a collaborative manner, working with the client and their family to gain a full understanding of the difficulties being experienced and determine the most effective way forward. They believe that by giving our clients choice about the treatment that they receive they can empower them and give them confidence. Their approach is therefore always flexible and geared to suit the needs of the client. The Asperger's & Autism Clinic part of Hampshire and Surrey Psychology is registered with the Health & Care Professions Council.</p>
Avenue Therapies	Autism assessment - adults	<p>The Autism Assessment service is comprised of Clinical Psychologists and a Clinical Nurse Specialist who all work and practice both in the public sector (i.e. in the NHS and Social Services) and privately. Through their work, they have noticed the increasing gap in service provision for Autism assessments for both adults and children. Their focus is to try and help meet the need of those who would not be able to access this service through the NHS, or other charity organisations, and would find it helpful to explore the difficulties they are experiencing.</p> <p>They are a team of qualified Clinical Psychologists and Nurses experienced in working with children, adult and family services within the NHS and Social Services. They are passionate about helping people of all ages and their families in understanding whether a diagnosis of Autism might explain your experiences and to use this information to guide future support and/or intervention.</p> <p>They offer assessments for people 18 years and above.</p>

Market analysis - Surrey

Organisation	Category	Summary of service
Jigsaw Plus	Specialist day services- adults	<p>JigsawPlus offers specialist day services for adults with an autism spectrum disorder (autism) and other disabilities. They are dedicated and passionate in their commitment to support adults with autism through lifelong learning opportunities JigsawPlus is a positive environment with highly trained, committed staff delivering person-centred support and learning programmes designed to promote positive personal choices, enhanced wellbeing, independence and social inclusion. The service is based at our Centre for Lifelong Learning on Dunsfold Park, Cranleigh in Surrey.</p> <p>JigsawPlus is open for 49 weeks per year. Placements are welcomed from across Surrey and surrounding counties. Open Mornings are run throughout the year for anyone interested in visiting and learning more about JigsawPlus</p>
Mindsight Surrey CAMHS - Surrey and Borders Partnership NHS Foundation Trust, Xenzone, Surrey Family Services, the National Autistic Society, Barnardo's, Relate West Surrey, Step by Step, Heads Together, Brain in Hand, Eikon, and Learning Space	Autism and ADHD assessment – children and young people	<p>Mindsight Surrey CAMHS is a partnership of expert organisations including Xenzone, Surrey Family Services, the National Autistic Society, Barnardo's, Relate West Surrey, Step by Step, Heads Together, Brain in Hand, Eikon, and Learning Space. Our wide range of dynamic, high performing partners are working with them to deliver greater support to more children and young people with the aim of reaching them before they become very unwell. Through a single point of referral, we offer a 'no wrong door' approach, providing support to children, young people and families to find the right help at the right time.</p> <p>They provide help and support to children and young people when they begin to feel emotionally or mentally unwell to build wellbeing and resilience to reduce the chances of their condition becoming more serious.</p> <p>Together with their partners they deliver targeted and specialist services, connecting with universal services to ensure support is available at entry level, from primary mental health in schools through to urgent needs.</p> <p>Service Description This service is responsible for providing all follow up appointments for children and young people who have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (autism).</p> <p>Areas Covered</p> <ul style="list-style-type: none"> •Runnymede •Spelthorne •Woking <p>Referral Process We only accept referrals from health, social care and education professionals.</p>

Market analysis - Surrey

Organisation	Category	Summary of service
National Autistic Society		<p>Local groups</p> <p>The National Autistic Society Surrey Branch is run by parent-volunteers and has a number of support groups for parents/carers.</p> <p>There are also a number of Surrey family support groups run by parents and carers who have children with autism and SEN.</p> <p>Support for parents</p> <p>The National Autistic Society's (NAS) Autism Family Support Service provides information, advice and support to the parents and carers of children and young people with autism in Surrey.</p> <p>The NAS also offer a Parent to Parent confidential telephone support service and an Autism Helpline that provides impartial and confidential information, advice and support.</p>
Various	Training for parents	<p>Courses for parenting a child with autism</p> <p>Barnardos Cygnet parent/carer support programme is designed for parents and carers of children and young people aged 5-19 years with an autism spectrum condition (ASC).</p> <p>Child Autism UK (formally, PEACH) offer ABA training sessions to parents to show them how to teach their child, manage behaviour and track progress.</p> <p>Positive Autism Support and Training (PAST) offer training to parents who have children with autism on topics including communication, behaviour, sensory issues, and support strategies.</p> <p>Parenting Autism Together – Preschool Programme (PAT-P) is a six week programme for Surrey parents and/or carers of preschool children with autism. It provides parents and carers with information to support their understanding of autism, strategies to support their child at home and an opportunity to build a network of support with other members of the group.</p> <p>Family support</p> <p>Sibs understand that a diagnosis of autism impacts the whole family, not just the individual. They aim to enhance the lives of siblings by providing them with information and support.</p> <p>Positive Autism Support and Training (PAST) also offer one-to-one support, small group training sessions and support to siblings of an autistic child.</p>

Market analysis - Surrey

Organisation	Category	Summary of service
Patchwork	Support for families	<p>Patchwork Autism Support offer practical advice and strategies for families supporting individuals with autism. They are an independent service offering practical advice and strategies for families and professionals supporting individuals with an autistic spectrum disorder.</p> <ul style="list-style-type: none"> •Home based appointments / consultations •1:1 work with you and your child •Holistic and child-centred approach to supporting you and your child •Practical and individualised strategies to use in the home •Strategies for everyday living and experiences •Support for specific events and activities e.g. weddings, holidays, meals out etc. •Coping with change e.g. changing schools, divorce, moving house etc. •Support with communication •Support with play and leisure skills •Support with life-skills and developing independence <p>They offer bespoke training packages for:</p> <ul style="list-style-type: none"> •nurseries •schools •colleges •employers •family attractions
	Support for families	<p>•Positive Autism Support and Training (PAST) offer training and provide support services to families who have children with autism and associated conditions. Support & advice for families of children and teenagers with Autistic Spectrum Conditions including Pathological Demand Avoidance (PDA) and other conditions. Anxiety and Anger Management Programmes</p> <ul style="list-style-type: none"> •One to One Bespoke Behavioural Support •Siblings Support •Social Skills Clubs •Autism Awareness Training for Parents •Initial Autism and ADHD Assessments <p>They also offer training to schools.</p>

Market analysis – Surrey cont.

Organisation	Category	Summary of service
Various	Short breaks/respite	<p>Surrey Short Breaks for Disabled Children funds voluntary organisations and SEND schools to provide short break services, including after school clubs, holiday schemes, home-care and more.</p> <p>GP Carer Breaks Payments are one off payments authorised by a carer's doctor (GP) in order to provide them with a respite from their caring role.</p> <p>Parent Carer Breaks Grants are payments made to support parents who have a disabled child under 18 living in Surrey, who are not currently receiving services from Surrey County Council children's services / don't have a social worker.</p>

Market analysis - Wiltshire

Organisation	Category	Summary of service
Virgin Care	CAMHS	<p>Community Paediatricians investigate and diagnose Autism.</p> <p>A healthcare professional (e.g. GP) should refer children into the service if they feel it is appropriate. After a referral, questionnaires may be sent out for parents to complete about their child. Sending these back quickly will speed up the process.</p> <p>The parent and child will be seen in a clinic room which should be relatively near to their home. The doctor will talk through concerns and worries. They will ask questions about the parent and the child's medical history, questions about their family and about the child development and progress.</p> <p>The doctor may then ask some more specific questions relevant to Autism. They may check the child's height and weight and examine them.</p>
Virgin Care	Childrens ADHD	<p>A healthcare professional (e.g. GP or health visitor) will refer the child into the service if they feel it is appropriate. They investigate and diagnose ADHD. There is no cure for this condition but behavioural strategies can be helpful. Sometimes they use medication to help the symptoms of ADHD. The child would need to be seen regularly by one of the team if they need medication.</p> <p>The parent and child is seen in a clinic room relatively near to their home. The doctor talks through concerns and worries. They will ask questions about the parent and the child's medical history, questions about their family and about the child development and progress.</p> <p>The doctor may then ask some more specific questions relevant to ADHD. They may check the child's height and weight and examine them. The doctor will gather information and complete a formal rating scale to see if the child meets the diagnostic criteria for ADHD. They will get information from home and school.</p>
NHS Avon and Wiltshire Mental Health Partnership	Adults autism	<p>Wiltshire Autism Diagnostic Service</p> <p>The Wiltshire Autism Diagnostic Services is a small multidisciplinary team providing an autism spectrum condition (ASC) assessment service to adults with a Wiltshire GP. They are able to offer a limited amount of post diagnostic support which is mainly to help people with an ASC to learn about the condition and to access a range of appropriate mainstream services.</p> <p>The team currently consists of an Occupational Therapist/team manager, registered nurses and administrative staff.</p> <p>What do we do?</p> <p>The team offers:</p> <ul style="list-style-type: none"> Direct work Direct diagnostic assessments for individuals referred by their GP using the Choose and Book system or by letter Direct diagnostic assessments for individuals referred through secondary care mental health services Post-diagnostic support - psycho-education, coping strategies & signposting. Encouraging parents/carers/partners and other family members to be involved in the assessment process where appropriate and agreed Indirect work Jointly assessing for an autism diagnosis with mental health and learning disability clinical staff. <p>they do not hold a caseload or care coordinate, and are currently only able to accept referrals for people registered with a Wiltshire GP.</p>

Market analysis - Wiltshire

Organi sation	Cate gory	Summary of service
NHS Avon and Wiltshi re Menta l Health Partne rship	Adult s ADHD	<p>Bristol ADHD has a specialist team of doctors, psychologists, occupational therapist and nurses who work exclusively with adults who have ADHD. They receive referrals from many health professionals in the south-west and beyond.</p> <p>They can reassess and continue treatment of people who have a diagnosis of ADHD from childhood, and also assess adults who have never had a diagnosis made. ADHD is quite a new diagnosis, with a lot of debate, even among professionals. Because of this, people think or get told that they have ADHD, when they don't. Equally often, it may be missed by professionals, including mental health professionals. There is a lot of information, advice and testing online and elsewhere, which may be misleading or wrong.</p> <p>Only an experienced expert can really assess and diagnose ADHD accurately because there are many other things about a person's life that need to be considered before a diagnosis of ADHD is made. ADHD is a lifelong diagnosis, so making the diagnosis requires a very thorough understanding of the patient.</p> <p>Referral and Assessment Process</p> <p>People need to see their GP or other health professional first.</p> <p>They could then refer them to their clinic for a specialist assessment. They will need to provide details about the person's childhood and current difficulties, and in particular how they feel ADHD has impacted on their life as an adult and as a child because ADHD is a lifelong condition. Going through their life story is necessary for a diagnosis to be made.</p> <p>Once the referral has been accepted, the person will be placed on their waiting list and a letter confirming this will be sent to them and the referrer.</p> <p>Shortly before an assessment appointment is offered, some questionnaires are sent to be completed about the person's life and ADHD.</p> <p>It is important they are completed and returned so that they are aware that they still wish to be assessed and that they can then book an assessment appointment.</p> <p>The assessment usually takes from two to four hours (which includes a break). The assessment takes this long so that they can really understand the person's whole life and history and be able to put their difficulties into context.</p> <p>Following the assessment, a report will be sent out to the person and their GP.</p> <p>If a diagnosis is made, they can offer treatment and further support.</p> <p>Treatments</p> <p>Medication for ADHD in line with national and international research into the condition</p> <p>Psycho-social interventions to help understand and master some of the ways ADHD affects people, for example administration, time management, and how to make the most of medication</p> <p>Peer support and skills group where the person can meet other people with ADHD and learn from them and the specialist team about techniques to help them in the real world managing the symptoms of ADHD.</p>

Market analysis - Wiltshire

Organisation	Category	Summary of service
Wiltshire Council	Parent training	<p>SWAPP is a partnership programme between parents and their child's setting or school that aims to build an understanding of autism and the challenges and delights it can present.</p> <p>The programme aims to empower families and staff who are closely involved in supporting a child or young person with autism. Sessions cover all aspects of autism including communication, sensory issues and behaviour.</p>
National autistic society	All ages	<p>Help line – providing advice and information Parent to parent telephone support Managing money</p> <p>The National Autistic Society has recently developed two new resources - a website and a workbook to help people on the autism spectrum learn about managing their money. Both are funded by the Consumer Financial Education Body (CFEB), as part of the National Strategy for Financial Capability. This covers all aspects of managing money, including opening a bank account, budgeting, and compulsive spending. It also includes video clips, interactive quizzes, questionnaires, downloadable resources and a virtual cash machine. Users need to register to use it and can then log back in to use the site whenever they want. The National Autistic Society has developed the site in consultation with people with an autism, who can use it independently or in a group or class setting.</p>

Appendix 7 Workforce analysis

List of contracts in relation to autism/ADHD support services

Commissioner	Contract	Value
East Berkshire CCG	Parenting Special Children	£29,989
	Autism Berkshire	£51,000
	The Autism Group	£16,971
	Ppepcare	£44,500
	Total	£142,260
Bracknell LA		
	Advocacy	*
	Dogs for good services	*
	Supported Living	*
	Excel Choice	£5,000
	Autism Berkshire	£6,000
	Total	>£11,000

- Services commissioned by **East Berkshire CCG** relate to pre and post diagnosis support for patients and families consisting of workshops, courses, home visits, and seminars.
- For **Bracknell**, Excel Choice and The Autism group receive a grant that is used as a contribution towards the cost of maintaining and developing the Bracknell Autism social group. The other services are general services that a person with autism/ADHD could be referred to.
- Slough** has not provided any information after repeated chasing.
- According to **RBWM**, the borough doesn't commission any services specifically for **adults** with autism or ADHD. Depending on an assessment of their needs, people with these conditions can access the same services as others e.g. advocacy, support at home. The only autism commissioning for **children** is a secondary school resource unit (SHINE) and the associated liaison with other schools. There is an autism focused free school (Forest Bridge) which operates on ABA principles and is entirely funded and monitored by the ESFA. The Achieving For Children services has a dedicated Autism lead who works part time supporting families and has 2 SENCOS working with schools. No values were provided.

Under 5s - autism : Workforce Community Paediatrics Service at BHFT



- As mentioned on the previous slide Berkshire Healthcare has a block contract arrangement with Berkshire East CCG, are not commissioned on a service line basis and therefore cannot put a value to annual contract funding.
- There are approx. 4.5 WTE consultant paediatricians, 1.2 WTE specialty doctors plus a variable cohort of doctors in training, usually one or two at any one time varying in seniority.
- In addition to that there is a long list of other duties as well as autism (adoption fostering, LAC, neurodisability, safeguarding etc etc) but paediatricians do have dedicated time in their job plans for autism assessment. The children will already have been seen by a paediatrician in a general clinic for holistic paediatric assessment prior to any autism assessment.
- Currently there is a consultant vacancy so the service is short of nearly 20% of paediatrician time.
- There are also vacancies within therapy services (so for instance this means that there is no OT input currently into community paediatric diagnostic assessments) and wait times for OT input when required post diagnosis are long. SaLT are currently also carrying vacancies.
- There is no clinical psychologist at all within the service, and there is no specialist HV or clinical nurse specialist as some services have.
- In the under-five age group in community paediatrics, there is no staff solely dedicated to autism; clinicians have a mixed caseload. For this reason an average caseload per WTE could not be provided.

Children over 5: Finance BHFT CAMHS in general

- Berkshire Healthcare has a block contract arrangement with Berkshire East CCG and are not commissioned on a service line basis therefore do not have an annual contract funding as such.
- The service provision to children with autism / ADHD is provided by not only services within CAMHS but also therapy services and paediatrician services and the data collection does not necessarily highlight provision according to diagnosis and therefore BHFT is not in a position to provide the financial information.
- The following slides summarise the workforce information and some benchmarking for CAMHS services

Workforce: Snapshot May 2019

Services	autism/ ADHD	WTE	Comment
Consultant Paediatricians	autism Under 5s	<ul style="list-style-type: none"> 4.5 WTE consultant paediatricians, 1.2 WTE specialty doctors plus a variable cohort of doctors in training, usually one or two at any one time varying in seniority, supported by therapy services. 	<ul style="list-style-type: none"> Paediatricians have dedicated time in their job plans for autism assessment, but other duties include adoption fostering, LAC, neurodisability, safeguarding etc Currently there is a consultant vacancy so the service is short of nearly 20% of paediatrician time. There is no clinical psychologist at all within the service, and there is no specialist HV or clinical nurse specialist as some services have. There are also vacancies within therapy services. There is no OT input currently into community paediatric diagnostic assessments and wait times for OT input when required post diagnosis are long. SalT are currently also carrying vacancies.
CAMHS	autism Over 5s	<ul style="list-style-type: none"> 0.8 WTE Autism Team Lead across East/West 4.1 WTE clinical staff for East Berkshire 	<ul style="list-style-type: none"> Staff from East and West are utilised to complete full assessments where possible meaning some flexibility 1.0 SLT WTE vacant (and out for advert); 0.6 SLT WTE is due to go on maternity leave in a few months. 0.4 has just been recruited to and is due to start in next few months.
	ADHD Over 5s	<ul style="list-style-type: none"> 1.0 WTE ADHD Team Lead 8a and 0.1 WTE Consultant Lead across East/West Total clinical staff 5.7 WTE for East 3 WTE assistant psychologists across autism/ADHD and East/West. Admin support for ADHD consists of 1 WTE band 4 (East and West) and 0.5 band 3 (East and West) 	<ul style="list-style-type: none"> 0.4 WTE vacancy for ADHD consultants. 0.8 ADHD nurse is due to leave this month but service has recruited to fill the posts starting the beginning of June with someone who wants to move from the West due to where they live. Some staff in the ADHD team have been trained to do joint ADHD/Autism assessments and some Autism staff do contribute to joint assessments (designed by the service) when capacity allows – as with the recent joint assessment funding that was provided as part of the waiting list initiative with East Berkshire. The objective is to do more joint assessments as usual practice. A large number of children present with both
Adults Service	autism (East/West)	<ul style="list-style-type: none"> Psychologist (8b – 0.4 WTE; 8a – 0.5 WTE) Cons. Psychiatrist (Medic) – 0.35 WTE Specialty Doctor (Medic) – 0.3 WTE Prescribing Pharmacist (8A) – 0.3 WTE Assistant Psychologist (b4) - 0.4 WTE Admin (b4) -1.0 WTE (+ 0.6 Bank) 	<ul style="list-style-type: none"> Total number of WTE for Adult autism assessment equals 2.45 WTE for East and West. 1.10 WTE of this total (based on 45% share in total referrals) would be dedicated to Berkshire East. There is one member of staff psychologist (8a) working across autism and ADHD
	ADHD (East/West)	<ul style="list-style-type: none"> Cons. Neuropsychologist (8d) – 0.3 WTE Psychologist (8a) – 0.6 WTE (+ 0.25 WTE Bank) SALT (B7) – 0.6 WTE Assistant Psychologist (B7) – 0.1 WTE Admin (B4) – 0.6 WTE 	<ul style="list-style-type: none"> Total number of WTE for Adult ADHD equals 3.85 WTE 1.75 WTE of this total (based on 45% share in total referrals) would be dedicated to Berkshire East There is one member of staff psychologist (8a) working across autism and ADHD

Children Over 5 – ADHD: CAMHS Workforce BHFT

- There is 1.0 ADHD Team Lead 8a across East and West Berkshire and 0.1 Consultant Lead across East and West Berkshire.
- Clinical staffing for ADHD in East Berkshire currently consists of 0.6 Consultant Psychiatrist WTE, 0.4 Speciality Doctor WTE, 1.7 Band 7 ADHD Nurse WTE and 3.00 Band 6 ADHD Nurse time WTE (see table below for split by Local Authority).

Role	Slough	RBWM	Bracknell	Total WTE
Consultants	0.2	0.2	0.2	0.6
Specialty Doctor	0	0	0.4	0.4
Band 7 Nurse	0.35	0.35	0.5	1.7
Band 6 Nurse	1.0	1.0	1.0	3.0
Total	1.55	1.55	2.1	5.7

“Some staff in the ADHD team have been trained to do joint ADHD/Autism assessments and some Autism staff do contribute to joint assessments (designed by the service) when capacity allows – as with the recent joint assessment funding that was provided as part of the waiting list initiative with East Berkshire. The objective is to do more joint assessments as usual practice. A large number of children present with both.”

- There is 0.4 vacant for ADHD consultants. 0.8 ADHD nurse is due to leave this month but service has recruited to fill the posts starting the beginning of June with someone who wants to move from the West due to where they live.
- In terms of non clinical and support staff for ADHD, there are
 - 3 WTE assistant psychologists that work across ADHD and Autism East and West.
 - Admin support for ADHD consists of 1 WTE band 4 (East and West) and 0.5 band 3 (East and West)

Children Over 5 – autism: CAMHS Workforce BHFT

- Staff from East and West are utilised to complete full assessments where possible meaning some flexibility
- There is 0.8 Autism Team Lead across East and West Berkshire

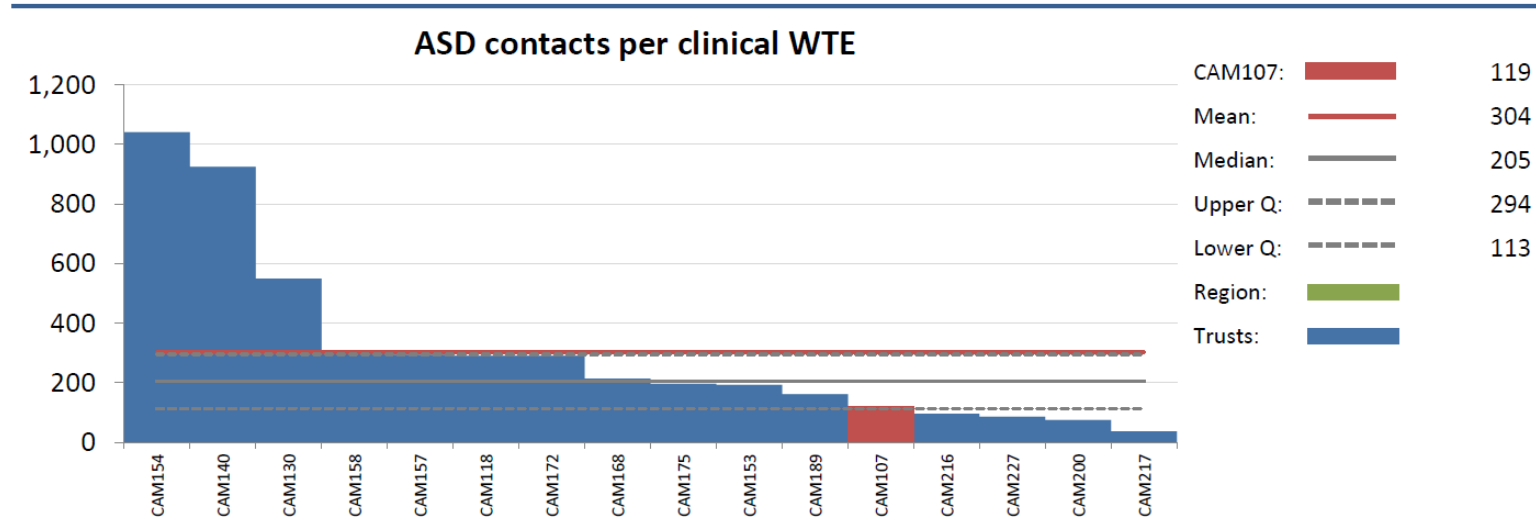
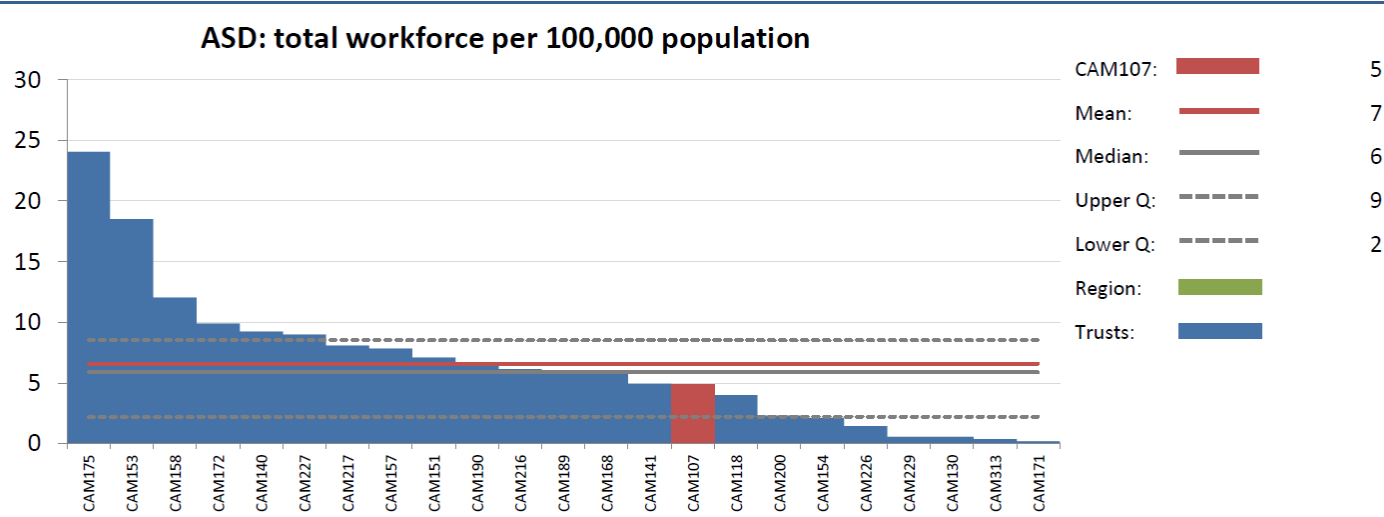
Role	Grade	WTE
Psychology	8a	0.2
Psychology	7	1.6
SLT	7	1.7*
SLT	6	1.4
Total		4.1

- There is a total 4.1 WTE clinical staff for East Berkshire (see break down by grade in table below)
- 1.0 wte SLT vacant (and out for advert); 0.6 SLT WTE is due to go on maternity leave in a few months. 0.4 has just been recruited to and is due to start in next few months.
- Total CAMHS autism workforce per 100,000 population (see next slide) for BHFT is equal to 5 WTE which is lower than national value of 7 WTE per 100,000 (Source CAMHS benchmark report 2018)

Summary CAMHS Benchmarking on autism (1)

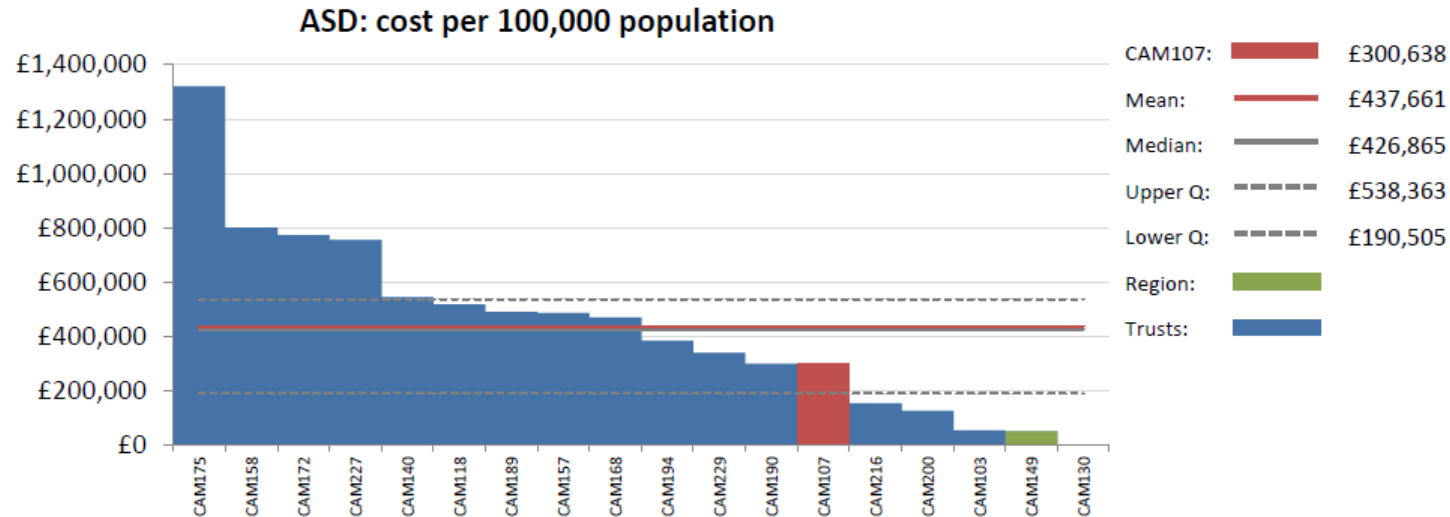


Total CAMHS autism workforce per 100,000 population for BHFT is equal to **5 WTE which is lower than national value of 7 WTE per 100,000** (Source CAMHS benchmark report 2018)



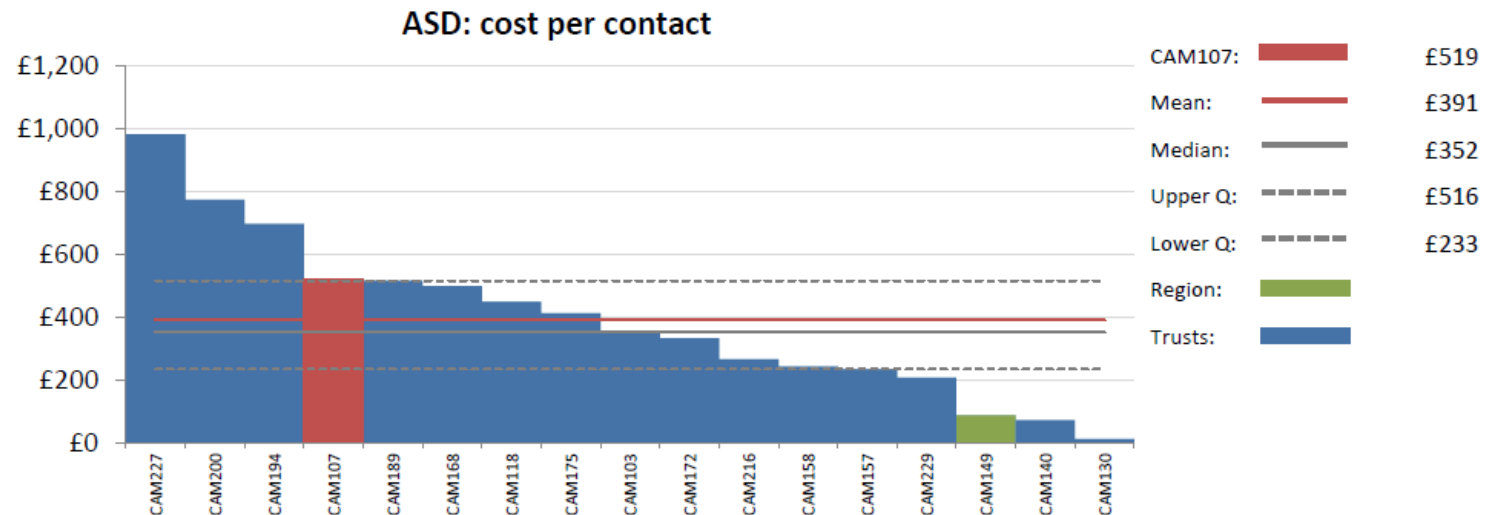
autism workforce is showing **low caseload** (119) per WTE compared to national average of 304, but similar to the regional average.

Summary CAMHS Benchmarking on autism (2)



CAMHS autism **costs per 100,000 population** are much lower than **national or regional levels**, which is **due to the smaller caseload** (see previous slide) that is held by the teams.

However, costs per contact are higher, with an average cost of £391 per year.



Adults – autism: Workforce at BHFT

- Total budget for the autism/ADHD combined (which hasn't changed since 2013) is approximately £65k per year for East Berkshire.
- Total number of WTE for Adult autism assessment equals **2.45 WTE** for East and West.
- **1.10 WTE** of this total (based on 45% share in total referrals) would be dedicated to Berkshire East.

Role	Grade/Band	Headcount	Total WTE
Cons. Neuropsychologist	8D	1	0.3
Psychologists*	8a	3	0.6
Psychologist- Bank	B7	1	0.25
SALT	B7	1	0.6
Asst Psychologist	B4		0.1
Admin	B4	1	0.6
Total		7	2.45

Adults - ADHD: Workforce at BHFT

Role	Grade/Band	Headcount	Total WTE
Psychologist	8B	1	0.4
Cons. Psychiatrist	Medic	1	0.35
Speciality Doctor	Medic	1	0.3
Prescribing Pharmacist	8a	1	0.3
Psychologist*	8a	2	0.5
Asst Psychologist	B4	1	0.4
Admin	B4	1	1.0
Admin-Bank	B4	1	0.6
Total		9	3.85

- Total number of WTE for Adult ADHD equals **3.85 WTE**
- **1.75 WTE** of this total (based on 45% share in total referrals) would be dedicated to Berkshire East

* There is one member of staff working across autism and ADHD

Adults – autism and ADHD: Workforce at BHFT

- Total budget for the autism/ADHD combined (which hasn't changed since 2013) is approximately £65k per year for East Berkshire.
- Total number of WTE for Adult autism assessment equals **2.45 WTE** for East and West.
- **1.10 WTE** of this total (based on 45% share in total referrals) would be dedicated to Berkshire East.

Role	Grade/Band	Headcount	Total WTE
Cons. Neuropsychologist	8D	1	0.3
Psychologists*	8a	3	0.6
Psychologist- Bank	B7	1	0.25
SALT	B7	1	0.6
Asst Psychologist	B4		0.1
Admin	B4	1	0.6
Total		7	2.45

Adults - ADHD: Workforce at BHFT

Role	Grade/Band	Headcount	Total WTE
Psychologist	8B	1	0.4
Cons. Psychiatrist	Medic	1	0.35
Speciality Doctor	Medic	1	0.3
Prescribing Pharmacist	8a	1	0.3
Psychologist*	8a	2	0.5
Asst Psychologist	B4	1	0.4
Admin	B4	1	1.0
Admin-Bank	B4	1	0.6
Total		9	3.85

- Total number of WTE for Adult ADHD equals **3.85 WTE**
- **1.75 WTE** of this total (based on 45% share in total referrals) would be dedicated to Berkshire East

* There is one member of staff working across autism and ADHD

Workforce Adults – Average caseload

Profession	Case Load
ADHD- Psychology	530
ADHD Group	5
ADHD- Review	47
ADHD- Medical	217
autism	489
autism-Group	17

- The table shows average caseload for West and East Berkshire with approx. 530 caseload for ADHD and 489 for autism assessment.
- Specifically for East Berkshire these numbers equate to 240 and 220 for ADHD and autism respectively (based on know 45% share of total referrals)
- Average caseload numbers have been extracted from Tableau and they include referrals waiting and seen, At the moment the service is working to bring these caseload figures in line with manual numbers but gives a sense of breakdown by teams and capacity.

BHFT autism/ADHD spend headlines

Berkshire Healthcare are commissioned by East Berkshire CCG on a block contract. As such, total spend on autism and ADHD clinical services is unknown. What we do know from other sources is that:

Under 5's

- Community paediatrics service employs 4.5 wte consultants, 1.2 WTE specialty doctors and supporting therapy staff
- Not fully dedicated autism/ADHD staff
- Waiting times are 6 to 18 months

Over 5's

- CAMHS autism spend of £300k per 100,000 population is lower than national and regional levels (£430k)
- As such, total CAMHS autism workforce per 100,000 population and average caseload is a lot lower than national

Adults

- Total annual funding for adult autism/ADHD services at BHFT is around £65k for Berkshire East
- This does not cover the cost of the three WTE dedicated autism /ADHD staff

Based on the information that is available and has been shared with us, between £150k and £200k of non-clinical support services (i.e. pre-post diagnosis support) is currently being commissioned by the CCG and LAs

Appendix 8

Summary of model options and appraisal

Scope

The market analysis has focused primarily on East Berkshire with some consideration to geographies on the boundaries of the area.

The analysis considers a range of different types of competitors, which includes:

- Mental health and community health providers
- Community health providers
- National private providers
- 3rd sector organisations

The analysis has looked at key providers of autism/ADHD services locally and surrounding areas an overview of their provision, where this information is publicly available can be found in the appendix 4.

Option appraisal

This section describes the options appraisal that has been completed, this includes:

- The rationale for the criteria and how this has been applied to the assessment
- The options and the assessment of these at sub-criteria level based on the feedback received from stakeholders in the engagement phase; and
- How this has informed the recommended option for further decision making and development of next steps

Assessment criteria

An 'option' describes the potential commissioning model for ADHD/autism services will be delivered. A set of 'hurdle criteria' has been established to provide an objective a view as possible of the options against each sub-criteria. It is acknowledged however that this may be open to interpretation. This hurdle criteria has been applied to the assessment criteria based on the feedback from stakeholders. A visual indicator known as a RAG rating (Red, Amber and Green) is used for the application of the hurdle criteria against each sub-criteria - these are categorised as per the table below.

	Description
●	Not Possible (legal or procurement framework does not allow) or high material risk to delivery
●	Possible but material risk to delivery
●	Possible and Deliverable

An assessment table has been created for each option which shows the hurdle criteria indicator assigned to each sub-criteria with assessment notes, explaining the rationale for the Provider's view. Accompanying this is a narrative summary of each option.

Assessment criteria

	Assessment Criteria		Description
Effective governance and accountability			
1a	Stakeholder Influence		Allows all commissioning organisations the ability to exercise effective influence over decision making
1b	Professional Governance and Outcomes		Allows the effective delivery of professional (including clinical and practitioner) governance and outcomes
1c	Organisational Sustainability		The form must be a robust vehicle which is sustainable and able to stand up and respond to political/regulatory changes/challenges
Effective delivery of the new model of care (inc. NICE Compliance)			
2a	Scope of Services		Delivers the scope of services identified by stakeholders
2b	Workforce Capability		Workforce experience/quality (attractiveness for employment)
2c	Service User Acceptability		Assessment of ease of delivering option in terms of public and stakeholder acceptability
2d	Activity shifts		Assessment of ease of creating required capacity shifts within timescales (workforce and physical facilities)
2e	Integration		Degree of integration across: education, local authority, primary, community, acute, and mental health services
2f	Transition Timeframes		Able to transition to new form in line with timeframes identified
Quality of Care / Improved outcomes			
3a	Service User/Patient Experience		Enables delivery of quality services, personalised care
3b	Service quality		Services to conform with best practice / guidelines
3c	Patient experience		Reduction in complaints and positive feedback
Access to care			
4a	Service User/Patient Choice		Enables commissioners to maintain choice for services users and a plural market
4b	Care closer to home		Proportion of visits/interventions delivered locally in the community or in patients' homes (inc. physical access)
Affordability and value for money			
5a	Affordability		Costs are fully understood and are affordable - Assessment of affordability within commissioners allocations
5b	Wider public sector/system pressures		Wider implications (beyond those areas in scope) resulting from the implementation of this form are understood and are acceptable
5c	Risks and Benefits		Able to manage risks and benefits, particularly financial

Assessment option 1 – Do nothing

The first option is to retain the current service model and pathways. This option would require no new investment, but would mean that:

- a) services are not compliant with NICE guidelines,
- b) there would remain a patchwork offer of pre diagnosis support and diagnosis provision across all age groups,
- c) A continuation of no post diagnostic support across all age groups,
- d) the waiting times would increase in theory and therefore become unsustainable in the longer term,
- e) negative impact on the education and quality of life for the children, young people, families and adults involved,

This option does not represent a pragmatic approach to care and support for these vulnerable groups. This is not a favoured option for stakeholder across the system and service users and parents/carers.

Scope

The proposed scope of this option is the currently community paediatrics service for children with autism or ADHD, CAMHS and adults autism/ADHD services plus 3rd sector support service for children's and adults.

Assumptions

In this option we assume that the current arrangements, including the interim pathway, stay as they are. This includes the current funding arrangements.

Impact on the Incumbent providers

Clearly this option is likely to limit the overall services in their ability to handle increasing volumes/improved quality without increasing the financial envelope. Whilst all costs are on a block basis, thus limiting cost increases in the short-term the demand on the service is clearly going to increase and therefore further funding would be required to meet this demand in the long term or the waiting lists will continue to grow.. On this basis alone one would call into question the long-term sustainability of the both the current core service as well as the supporting service contracts. Allied to this cost driver, clear shortfalls in service scope, quality, and delivery, would be very difficult to address in the current fractured commissioning and delivery environment.

Assessment option 1 – Do nothing

Here is the detailed assessment of this option:

			Description
Effective governance and accountability			
1a		●	The current commissioning arrangements are fragmented – several services are provided and commissioned by different parties leading to ineffective performance management.
1b	Professional Governance and Outcomes	●	There is a lack of grip on service delivery, especially service user outcomes.
1c	Organisational Sustainability	●	This option will continue to have fragmented services and interim arrangements. This includes additional investment into an interim pathway to continue to deliver diagnosis.
Effective delivery of the new model of care (inc. NICE Compliance)			
2a	Scope of Services	●	As described within Section 3 services are fragmented and do not comply with NICE guidelines. There is a lack of support for parents also and service gap from 16-18.
2b	Workforce Capability	●	There is a good level of workforce capability across the system but skills are not deployed in the most effective way. The model is medicalised in nature. The current provision is not an attractive service to work in.
2c	Service User Acceptability	●	Evidenced by the level of complaints service users and parents/carers are very unhappy with these services.
2d	Activity shifts	●	This option would not shift or deflect activity.
2e	Integration	●	There is minimal integration across other services, including schools.
2f	Transition Timeframes	●	This will be a continuation of the current services, therefore, transition arrangements will not be required.
Quality of Care / Improved outcomes			
3a	Service User/Patient Experience	●	Services are currently formulaic and are not flexible enough to respond to service user needs. Concerns have also been made in relation to medication reviews and drug holidays.
3b	Service quality	●	Services do not comply with NICE guidelines.
3c	Patient experience	●	As evidenced there is a high backlog for these services and many delays in diagnosis. This has created a number of complaints from service users/parents/carers.
Access to care			
4a	Service User/Patient Choice	●	Services are currently delivered under a block contract with some activity arrangements in place.
4b	Care closer to home	●	Parents have complained about travel, also the hospital environment is not the best environment for service users. Community Paediatricians do travel out in the county to provide services.
Affordability and value for money			
5a	Affordability	●	This option represents the current level of investment and would not require any further investment.
5b	Wider public sector/system pressures	●	We do not expect this to impact on any other services.
5c	Risks and Benefits	●	The main risk is a continuation of poor feedback from service users, services not compliant with NICE Guidelines, ongoing delays for assessment/diagnosis and lack of grip on performance.

Assessment option - 2

Create a standalone 0 – 18 autism/ADHD service, that provides diagnosis and medication reviews. Consider widening out training those who can diagnose in the community, e.g. advanced nurse practitioners who can also prescribe and GPs with special interest also use of on line assessment. The service would work in a integrated virtual way with LAs, schools and 3rd sector. Increase OT provision as part of assessment MDT.

This second option would be achieved by merging the current autism and ADHD Community Paediatrics services and CAMHS services via a revised specification and contract variation to the BHFT contract which is contract managed by the CCG.

In this option we seek to remove some professional barriers and start to integrate services. However, services post-diagnosis would not be addressed.

Scope

The proposed scope of this option is the current Community Paediatrics, CAMHS and adults autism and ADHD services provided by BHFT . The current services diagnose children from the age of 0 – 5, 6 – 18 and adults.

Assumptions

In this option we assume that the current arrangements for Community Paediatrics are merged with CAMHS. Access to therapies would need to be secured. Other assumptions include:

12 month notice period – allowing new service to commence 12 months later - this could be negotiable.

There is no TUPE implication but would require staff-side negotiation

Assessment option - 2

Impact on the Incumbent provider

BHFT would need to explore the feasibility of splitting/reorganising resources – physically/professionally – from their existing environment. This might lead to more specialisation but equally could open up broader opportunities/synergies in a broader CAMHS and adult environments.

Clearly such a transformation of service would need to be approved by the BHFT board and from a commissioning perspective be compliant with any current contract clauses.

The service transformation would provide an opportunity to put in place new and more effective governance that might include single medical/performance leads representative of the CCG as well as the LA to ensure coordination with related services. Alternatively, the commissioning/oversight of this service could be led by a designated LA via a section 75 agreement. This could strengthen the overall integration/coordination with related services, including educational, as well as CAMHS/adults.

This option along with option 3 and 4 potentially provide the opportunity to gain improvements in service quality/activity through the integration of people, skills, back office services, and better coordination. Clearly the greater the integration then the greater opportunity for improvements but also the larger the challenge in re-engineering a new service via re-design, specifications, and/or procurement.

Assessment option - 2

Here is the detailed assessment of this option:

	Assessment Criteria		Description
Effective governance and accountability			
1a	Stakeholder Influence	●	There are existing contract management mechanisms in place for CAMHS, therefore, this is quite an attractive option for commissioners.
1b	Professional Governance and Outcomes	●	This option would improve professional governance, however there is a risk that autism/ADHD services do not get the required focus to improve outcomes for this patient cohort
1c	Organisational Sustainability	●	This option will continue to have fragmented services. Arrangements would need to be in place with SALT and OT, for example, to deliver multi-disciplinary diagnosis.
Effective delivery of the new model of care (inc. NICE Compliance)			
2a	Scope of Services	●	As described services are fragmented and do not comply with NICE guidelines. This option would move a % of the community paediatrician services to CAMHS. Therapies would be missing.
2b	Workforce Capability	●	There would be better integration between psychiatry and paediatricians. The model would continue to be medicalised in nature.
2c	Service User Acceptability	●	This option would be more acceptable to service users than 'do nothing'
2d	Activity shifts	●	This option would not shift or deflect activity as there is no significant service redesign.
2e	Integration	●	This model is still health orientated, therefore, there would still be minimal integration across other services, including schools.
2f	Transition Timeframes	●	This option would be commissioned by a managed change process, which would be to negotiate a contract variation with BHFT. This option could be delivered fairly quickly.
Quality of Care / Improved outcomes			
3a	Service User/Patient Experience	●	This option would see a more holistic assessment of the service user as there would be better integration between psychiatry and paediatricians. Psychologist involvement could enhance cognitive behaviour support.
3b	Service quality	●	Services will not comply with NICE guidelines and the changes would make little impact on making the services compliant.
3c	Patient experience	●	A fairly high number of complaints from service users/parents/carers would be anticipated.
Access to care			
4a	Service User/Patient Choice	●	Choice of services is expected to be limited.
4b	Care closer to home	●	Facilities are expected to be more child friendly – and further options would be added that are utilised for CAMHS
Affordability and value for money			
5a	Affordability	●	This option represents the current level of investment but would require investment for therapy services and most likely a sub-contract to secure those services. However, we would expect to see better value for money.
5b	Wider public sector/system pressures	●	We do not expect this to impact on any other services.
5c	Risks and Benefits	●	The main risk is a continuation of poor feedback from service users, services not compliant with NICE Guidelines, ongoing delays for assessment/diagnosis. The risk is also the interface with therapy services

Assessment option - 3

Create a standalone 0 – 25 autism/ADHD service, in line with SEND that provides diagnosis and post diagnosis support which includes an intensive support function helping people to stay at home reducing unnecessary inpatient placements and better transition from inpatients to the community. Consider widening out training those who can diagnose in the community, e.g. advanced nurse practitioners who can also prescribe and GPs with special interest also use of on line assessments. The service would work in a integrated virtual way with LAs, schools and 3rd sector. Increase OT provision as part of assessment MDT.

This third option would be achieved by merging the current autism and ADHD Community Paediatrics services, CAMHS and Adults services via a revised specification and contract variation to the BHFT contract which is contract managed by the CCG.

In this option we continue to seek to remove some professional barriers and start to integrate services. Additional resources would most likely be needed to enable the service to provide post-diagnosis support when needed.

Scope

The proposed scope of this option is the current Community Paediatrics, CAMHS and adults autism and ADHD services provided by BHFT. The current services diagnose children from the age of 0 – 5, 6 – 18 and adults.

Assessment option - 3

Assumptions

In this option we assume that the current arrangements for Community Paediatrics, CAMHS and adult autism and ADHD services are merged. Access to therapies would need to be secured. Other assumptions include:

- 12 month notice period served – allowing new service to commence 12 months later - *this could be negotiable.*
- There is no TUPE implication but would require staff-side negotiation

Impact on the Incumbent provider

BHFT would need to explore the feasibility of splitting/reorganising resources – physically/professionally – from their existing environment. This might lead to more specialisation but equally could open up broader opportunities/synergies in a broader CAMHS and adult environments.

Clearly such a transformation of service would need to be approved by the BHFT board and from a commissioning perspective be compliant with any current contract clauses.

The service transformation would provide an opportunity to put in place new and more effective governance that might include single medical/performance leads representative of the CCG as well as the LA to ensure coordination with related services. Alternatively, the commissioning/oversight of this service could be led by a designated LA via a section 75 agreement. This could strengthen the overall integration/coordination with related services, including educational, as well as CAMHS/adults.

This option along with option 3 potentially provide the opportunity to gain improvements in service quality/activity through the integration of people, skills, back office services, and better coordination. Clearly the greater the integration then the greater opportunity for improvements but also the larger the challenge in re-engineering a new service via re-design, specifications, and/or procurement.

Assessment option - 3

Here is the detailed assessment of this option:

Assessment Criteria			Description
Effective governance and accountability			
1a	Stakeholder Influence	●	There are existing contract management mechanisms in place for BHFT, therefore, this is quite an attractive option for commissioners.
1b	Professional Governance and Outcomes	●	This option would improve professional governance, however there is a risk that autism/ADHD services do not get the required focus to improve outcomes for this patient cohort
1c	Organisational Sustainability	●	This option will continue to have fragmented services. Arrangements would need to be in place with SALT and OTs for example, to deliver multi-disciplinary diagnosis. Plus 3 rd sector would not be part of this arrangement
Effective delivery of the new model of care (inc. NICE Compliance)			
2a	Scope of Services	●	As described, services are fragmented and do not comply with NICE guidelines. This option would move a % of the community paediatrician services, CAMHS and adults services into one service. Therapies would be missing.
2b	Workforce Capability	●	There would be better integration between psychiatry, paediatricians and adults . The model would continue to be medicalised in nature.
2c	Service User Acceptability	●	This option would be more acceptable to service users than 'do nothing'
2d	Activity shifts	●	This option could shift/deflect activity if there was significant service redesign.
2e	Integration	●	This model is still health orientated, therefore, there would still be minimal integration across other services, including schools and 3 rd sector.
2f	Transition Timeframes	●	This option would be commissioned by a managed change process, which would be to negotiate a contract variation with BHFT. This option could be delivered fairly quickly.
Quality of Care / Improved outcomes			
3a	Service User/Patient Experience	●	This option would see a more holistic assessment of the service user as there would be better integration between psychiatry and paediatricians and adult services. Psychologist involvement could enhance cognitive behaviour support.
3b	Service quality	●	Services will not comply with NICE guidelines and the changes would make little impact on making the services compliant.
3c	Patient experience	●	A fairly high number of complaints from service users/parents/carers would be anticipated.
Access to care			
4a	Service User/Patient Choice	●	Choice of services is expected to be limited.
4b	Care closer to home	●	Facilities are expected to be more child friendly – and further options would be added that are utilised for CAMHS
Affordability and value for money			
5a	Affordability	●	This option represents the current level of investment but would require further investment for therapy services and most likely a sub-contract to secure those services, and resource for post diagnostic support. However, we would expect to see better value for money.
5b	Wider public sector/system pressures	●	We do not expect this to impact on any other services.
5c 103	Risks and Benefits	●	The main risk is a continuation of poor feedback from service users, services not compliant with NICE Guidelines, ongoing delays for assessment/diagnosis. The risk is also the interface with therapy services

Assessment of Option 4

This option seeks to establish a fully integrated service for children, young people and adults. The commissioner would seek to commission a single provider with the accountability to deliver the autism and ADHD services currently commissioned by the CCG (i.e. a budget to deliver the services in scope and develop them in line with the autism/ADHD new model of care). The ambition would be to:

- Provide seamless and person centred services, based on outcomes
- Support ages 0 – 25 (in line with SEND)
- Focus on early intervention, help and support to prevent crisis
- Single point of access which would provide advice and guidance
- MDT approach – a consistent approach to assessment
- Services co-located, where possible
- Closer integration with schools and parent groups
- Provision of 3rd sector activities current commissioned e.g. autism/ADHD training for staff, parents, carers, partners and people with autism/ADHD, peer support groups, sleep support etc.

Assessment of Option 4

Service users, families and other stakeholders tell us that the features of this new model should include:

- Wider agency working and community support, plus information sharing across agencies.
- A single point of access and triage to enable feedback on referral and future commissioning. Triage will enable case management and personalised packages of care to be implemented, rather than more straightforward cases needing to follow an unnecessarily complicated process.
- Demand management strategies – to maximise the flow through the service. Community Paediatrics is currently the 'first port of call' for anyone with any signs of ADHD/autism. Entry and exit strategies need to be considered to maintain flow through the service and ensure services have capacity to see children, young people and adults for diagnosis, or those in need of more specialist care. Primary care services and other agencies may be able to aid this flow.
- Support packages to help families when concerns in suspected neurodevelopmental conditions are 'sub-threshold'. Services need to acknowledge these families' concerns and provide support, plus develop mechanisms to ensure such families are signposted to more appropriate services at the outset where possible.
- Transitions – consideration of early years to primary; primary to secondary and secondary to adult services need to be considered. The core neurodevelopmental behaviours are typically present in early childhood, although some features may not manifest until a change of situation, for example, the start of nursery or school or, less commonly, the transition to secondary school. The way in which autism and ADHD are expressed will differ across different ages and therefore for any individual may change over time as they mature.
- Use of digital technology and online resources – there may be options to explore in line with the ambitions around use of technology.

Scope - The proposed scope of this option is:

- | | |
|--|---|
| • The current Community Paediatrics service for children with autism or ADHD provided by ULHT. | • Emotional Wellbeing Service (Healthy Minds) (delivered by LPFT) |
| • Therapy services (delivered by LCHS) | • Sensory OT and SALT |
| • Full & seamless integration with a CAMHS Service (delivered by LPFT) | • Interfaces with IPC/Personal/Direct Budgets |
| • Behavioural Outreach Support Service (BOSS) | • 3 rd sector commissioned services |

Assumptions and impact

In this option we assume that services are redesigned and a new service model developed focusing on a less medicalised delivery model in line with the new model of care.

Impact on the Incumbent providers

This option provides a higher level of integration and thus economies in terms of back-office and administrative services. Clearly it could potentially improve quality by providing a more joined up service. Some of the impact on BHFT has already been dealt with in an earlier option and here we have a number of other organisations, players/staff who would be impacted.

From a commissioning perspective a central pot of money would need to be established and supported via a combination of co-commissioning, lead commissioning, and/or section 75 agreement. A lead organisation for the procurement would need to be established along with a governance process for both the procurement and ultimate service management. Given that the bulk of the services in terms of scope are currently led by the LA, then a nominated LA might be the natural lead for the process.

A big challenge here is to get the buy-in of all associated parties to a longer term integration so that they are either encouraged to bid or at least supportive of the process which would support cooperative/integrated bids. Equally, contracts can be amended/terminated in an orderly fashion, without conflict, and the need for forced de-commissioning of services.

Finally it would be essential to fully assess the impact of this option on some existing peripheral service providers – e.g. BOSS, Autism Berkshire, The Autism Group and Parenting Special Children etc.

In the case of option 3 and particularly for this option it might be important that a supplier landscape exists beyond local county boundaries. For example greater competition may lead to more innovation, value for money, and can fill the gap when local providers are not strong.

The brief initial market assessment indicates that there are many players in the market outside of the local geography and existing supplier network that could potentially be involved in new provider arrangements. Some of these are only to date local to their areas, but others have a national reach. Equally some providers focus on specific service elements, e.g. National Autistic Society,, others have taken on board much larger offerings, e.g. Virgin Care and Oxford Health NHS Foundation Trust.

Clearly it would be beneficial for both this option and the others that a common paper – proposal/business case – be written for presentation and approval at the various boards and committees. This would enable a review of the workforce involved and detailed costings of the options. It will also ensure consistency of message, debate, and prioritisation. The paper would naturally include any amended commissioning and governance arrangements that have been outlined within this report.

Assessment of Option 4

Assessment Criteria			Description
Effective governance and accountability			
1a	Stakeholder Influence	●	This would be a fully integrated contract. Contract and performance management arrangements would need to be confirmed, but commissioners would be very clear on services as a new specification would be developed.
1b	Professional Governance and Outcomes	●	This option would improve professional governance as the relevant skills would be employed (or sub-contracted) by the lead provider. All the skills required to deliver a successful service would be managed by the integrated service.
1c	Organisational Sustainability	●	This option would seek to contract with a single contracting entity (with a lead provider being most favourable). There would be very clear accountability for commissioners and providers for performance.
Effective delivery of the new model of care (inc. NICE Compliance)			
2a	Scope of Services	●	This model would seek to deliver a less medicalised model with the broadest scope of services. A key feature will be support to families which will help manage demand. The broader age range (0-25) will make transitions much more effective
2b	Workforce Capability	●	This option would seek to establish innovation from the provider market. For example Psychiatrists could take on the more challenging cases and there would be lower level support to undertake an early assessment of the service users before being referred to the service. Use of the voluntary sector would be advocated.
2c	Service User Acceptability	●	This option would be much more acceptable to service users than 'do nothing'. In particular the earlier intervention, better co-ordination, family support and post-diagnosis support would be welcomed
2d	Activity shifts	●	This option would seek shift or deflect activity significantly, managing demand by reducing referrals to the services and supporting parents, health visitors and schools to help manage childrens disorders.
2e	Integration	●	This model would have deep integration across health (primary, community, and CAMHS) and supporting services (for parents and schools)
2f	Transition Timeframes	●	This option would be commissioned by undertaking a competitive procurement exercise. The market analysis undertaken indicates that there is a competitive market for these services and the scope would attract a good level of interest. A procurement is expected to take over 12 months, and the contract scope could be phased over the lifetime of the contract.
Quality of Care / Improved outcomes			
3a	Service User/Patient Experience	●	This option would see a more holistic assessment of the service user as there would be better integration between services. There would also be earlier support and post-diagnostic support
3b	Service quality	●	This service has the potential to develop a great level of expertise as a specialist service. Services will comply with NICE guidelines (over time) and the changes would make a good impact on making the services compliant.
3c	Patient experience	●	This model should address many of the complaints that are currently being made. It also responds to the engagement that has been carried out.
Access to care			
4a	Service User/Patient Choice	●	Choice of services is expected to be managed in an effective way, signposting users to services provided by voluntary sector, as well as the statutory services.
4b	Care closer to home	●	Facilities are expected to be more child friendly – choice of facilities are expected to be more wide ranging and closer to the home
Affordability and value for money			
5a	Affordability	●	We would expect to see better value for money, utilising lower level skills to manage demand more effectively and specialist skills to manage more challenging cases. However, investment may be required to ensure there is adequate funding to run the services. Single management, administration and systems could lead to improved productivity and efficiencies. Services could be brought back into area which may lead to savings.
5b 107	Wider public sector/system pressures	●	We expect this to have a positive impact on other services making interfaces easier to understand.
5c	Risks and Benefits	●	The main risk is whether the services are affordable.

Conclusion and recommendations

Below is a summary of the assessment of each of the options:

	Assessment Criteria	Option 1 – Do Nothing	Option 2 – Add to CAMHS	Option 3 – Add to CAMHS	Option 4 – Integrated Service
Effective governance and accountability					
1a	Stakeholder Influence	●	●	●	●
1b	Professional Governance and Outcomes	●	●	●	●
1c	Organisational Sustainability	●	●	●	●
Effective delivery of the new model of care (inc. NICE Compliance)					
2a	Scope of Services	●	●	●	●
2b	Workforce Capability	●	●	●	●
2c	Service User Acceptability	●	●	●	●
2d	Activity shifts	●	●	●	●
2e	Integration	●	●	●	●
2f	Transition Timeframes	●	●	●	●
Quality of Care / Improved outcomes					
3a	Service User/Patient Experience	●	●	●	●
3b	Service quality	●	●	●	●
3c	Patient experience	●	●	●	●
Access to care					
4a	Service User/Patient Choice	●	●	●	●
4b	Care closer to home	●	●	●	●
Affordability and value for money					
5a	Affordability	●	●	●	●
5b	Wider public sector/system pressures	●	●	●	●
5c	Risks and Benefits	●	●	●	●
	●	12	9	8	3
	●	2	6	6	-
	●	3	2	3	14

Option 4 has been assessed as the most beneficial option but further work would be required to fully establish and efficiencies that could be achieved together with the the level of investment required to provide a fully integrated 0 - 25 service. Options 2 and 3 provide a strong solution and would provide an opportunity to develop stronger interfaces with related services through the development of a clear service specification. The next slide outlines the potential efficiencies that could be achieved through implementing options 2 and 3.

Appendix 9 What is Autism and ADHD?

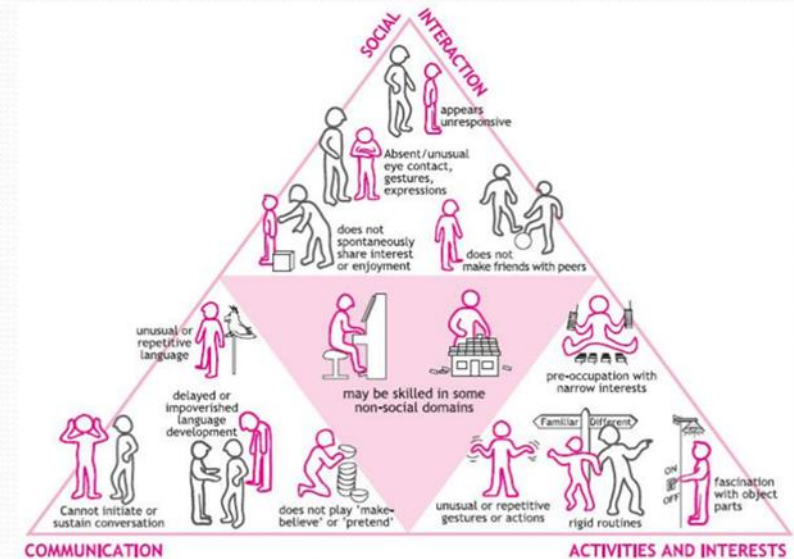
Autism is a lifelong developmental condition which affects the way that individuals communicate with and relate to other people. It affects how they make sense of the world around them. People with autism often prefer routine and may struggle with change. They may have particularly intense interests and may be good at noticing patterns and small details. People with autism frequently suffer from high levels of anxiety due to their difficulties in making sense of what is going on around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways.

Berkshire Healthcare Trust (BHT) can assess children if they're suspected of being on the autistic spectrum and are aged between **one and 17½ years in West Berkshire**, and **five and 17½ years in East Berkshire**.

<https://cypf.berkshirehealthcare.nhs.uk/our-services/mental-health-services-camhs/autism-assessment-team/>

Some autistic people can display challenging behaviour. It includes what would normally be considered physically aggressive behaviour, but can also include other behaviours if they are having a negative impact on the person or their family.

<http://www.autism.org.uk/challengingbehaviour>



National Autistic Society

Autism assessment and process

NHS Choices

A diagnosis of autism is based on the range of features a child is showing. Information is gathered from GP, nursery or school staff, plus speech and language and occupational therapists, about development, health and behaviour.

A speech and language therapist, and often an occupational therapist, will carry out an assessment

A detailed physical examination will be carried out to rule out possible physical causes of symptoms, such as an underlying condition like neurofibromatosis or Down's syndrome. The assessment will include a check for any coexisting physical health conditions and mental health problems

In addition, attendance at a series of interviews may be required to understand development and behaviour.

Once this process is complete, a diagnosis of autism may be confirmed.

There is no 'cure' for autism, but there are a range of specialist interventions that aim to improve communication skills and help with educational and social development. It can be difficult to know which intervention will work best for each child, as each person with autism is affected differently.

Some types of intervention can involve hours of intensive work, with pragmatic barriers because of the practical, emotional and financial commitments necessary.

Any intervention should focus on important aspects of the child's development. These are:

- **communication skills** – such as using pictures to help communicate
- **social interaction skills** – such as the ability to understand feelings and responses
- **imaginative play skills** – such as encouraging pretend play
- **academic skills** – the "traditional" skills a child needs to progress with their education

Attention Deficit Disorder

NHS Choices

Attention deficit hyperactivity disorder (ADHD) is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity and impulsiveness. Symptoms of **ADHD** tend to be noticed at an early age and may become more noticeable when a child's circumstances change, such as when they start school. Most cases are diagnosed when children are 6 to 12 years old. The symptoms of ADHD usually improve with age, but many adults who were diagnosed with the condition at a young age continue to experience problems.

People with ADHD may also have additional problems, such as sleep and anxiety disorders

[Attention deficit hyperactivity disorder \(ADHD\) - NHS](https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/)

<https://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/>

Berkshire Healthcare Trust ADHD Pathway is made up of an experienced multi-disciplinary team who assess and provide treatment for young people between the ages of 6-18.

Referrals should be made by a professional who has been able to observe the child, such as a special educational needs co-ordinator (SENCO) or an educational psychologist.

What causes ADHD?

The exact cause of ADHD is unknown, but the condition has been shown to run in families. Research has also identified a number of possible differences in the brains of people with ADHD when compared with those without the condition.

Other factors suggested as potentially having a role in ADHD include:

- being born prematurely (before the 37th week of pregnancy)
- having a low birthweight
- smoking, or alcohol or drug abuse during pregnancy

ADHD can occur in people of any intellectual ability, although it's more common in people with learning difficulties.

NHS Choices

A diagnosis of autism is based on the range of features a child is showing. Information is gathered from GP, nursery or school staff, plus speech and language and occupational therapists, about development, health and behaviour.

Although there's no cure for ADHD, it can be managed with appropriate educational support, advice and support for parents and affected children, alongside medication, if necessary.

Medication is often the first treatment offered to adults with ADHD, although psychological therapies such as [cognitive behavioural therapy \(CBT\)](#) may also help.

There are a number of different specialists a person may be referred to for a formal assessment, including:

- a child or adult psychiatrist
- a paediatrician – a specialist in children's health
- a learning disability specialist, social worker or occupational therapist with expertise in ADHD

Who people are referred to depends their age and what's available in their local area.

There's no simple test to determine whether a person has ADHD, but a specialist can make an accurate diagnosis after a detailed assessment.

NHS Choices cont:

The assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms
- a series of interviews with the person
- interviews or reports from other significant people, such as partners, parents and teachers

Diagnosing ADHD in children depends on a set of strict criteria. To be diagnosed with ADHD, the child must have 6 or more symptoms of inattentiveness, or 6 or more symptoms of hyperactivity and impulsiveness.

Diagnosing ADHD in adults is more difficult because there's some disagreement about whether the list of symptoms used to diagnose children and teenagers also applies to adults.

In some cases, an adult may be diagnosed with ADHD if they have 5 or more of the symptoms of inattentiveness, or 5 or more of hyperactivity and impulsiveness, listed in diagnostic criteria for children with ADHD.

As part of a person's assessment, the specialist will ask about their present symptoms. However, under current diagnostic guidelines, a diagnosis of ADHD in adults cannot be confirmed unless their symptoms have been present from childhood.

Appendix 10 Best practice service examples

Best practice early intervention

Organisation	Category	Summary of model
Bradford Born in Bradford project	Diagnosis pathway development.	<p>https://www.connectedhealthcities.org/research-projects/improving-pathway-diagnosis-autism-children/</p> <p>Current research underway as part of the Born in Bradford Project. Children with autism often wait many years before they are referred to a clinic that can diagnose the condition. This is often despite considerable family contact with different parts of the health service, and the child struggling within the school environment. Health professionals and teachers commonly lack the knowledge or confidence to suggest referral for assessment, and thus the pathway through the health service to get a diagnosis is often long and frustrating.</p> <p>The connection of routine health data with routine education data provides a potential way to understand and ultimately improve the pathway to autism clinic referral. This is of huge importance to families of children with the condition because there is considerable evidence that earlier diagnosis is associated with better outcomes. Moreover, early diagnosis will reduce the pressures placed on schools by children with undiagnosed autism, as well as lessening the burden on other clinics and limiting the need for the Child and Adolescent Mental Health Services to deal with the difficulties created when a child is diagnosed at an older age.</p> <p>Objectives of the project</p> <ul style="list-style-type: none"> •To quantify, map and model the current patient pathways through the health service leading to referral for autism assessment. •To look for associations between early years foundation stage assessment profile (a universal measure taken on all children at the point of school entry) and the diagnosis of autism as coded in routine health records (linking routine education and health data). •To pilot the use of routine educational data as a first stage in screening for autism by primary school teachers (using routine data to improve the pathway to autism assessment).
Bradford Born in Bradford project	Testing the early years foundation stage profile as an early screening for social communications and other developmental difficulties	<p>https://www.connectedhealthcities.org/research-projects/improving-pathway-diagnosis-autism-children/</p> <p>Current research underway by Hull York Medical School University of York as part of the born in Bradford project. Researchers are trying to identify children with developmental problems as early as possible. Following the end of reception year teachers carry out an early years foundation stage profile. These profiles can be very helpful in identifying health and additional needs. The research is planned to test this. Researchers are working with 10 schools to look at any child who has low scores on the early years foundation stage profile. Researchers are going to carry out more in-depth assessments which involve things like, talking to the teachers, observing the child in class, carrying out a play based assessment, talking with the parents., researchers are interested in a range of things not just language and numbers but social and emotional development, interested in the whole child. The research is likely to lead to improvements for children and for them to get help earlier.</p>

Best Practice early intervention

Organisation	Category	Summary of model
The Autism Resource Centre (ARC) is a partnership between Glasgow City Council, NHS Greater Glasgow & Clyde , The National Autistic Society , Scottish Autism and Strathclyde Autistic Society	One stop shop	<p>The Autism Resource Centre in Glasgow was one of the original One-StopShops set up by the Scottish Government and has now been operating for 10 years. It is a partnership between Glasgow City Council, NHS Greater Glasgow, the Scottish Society for Autism, the National Autistic Society and Strathclyde Autistic Society. An evaluation after the first two years (2004- 2006) found that 87% of people with autism who used the service felt that their overall experience at the Centre was ‘very positive’ or ‘positive’ (Marwick and Tait, 2006). Most found that the service met their needs and that it is the one safe place they can go to relax and be understood and they outlined a range of benefits from their contact with the centre. Most parents and carers (69%) felt that their overall experience of the Centre was ‘very positive’ or ‘positive’. The results indicated that the Centre is meeting its aims in relation to service users.</p> <p>The service works with the Adult Autism Additional Support Team, led by the ARC’s Speech and Language Therapist, and with Children’s autism services to help make sure people on the autism spectrum and their families receive the most effective care possible.</p> <p>The work of the ARC is guided by the Autism Working Group, with members from the statutory and voluntary sectors, and individuals with Autism Spectrum Disorders, parents and the National Centre for Autism Studies. This helps ensure that the ARC delivers the services it should.</p> <p>Services available:</p> <ul style="list-style-type: none"> • Information services • One-to-one guidance • Services for adults with Autism Spectrum Disorders (autism) • Promoting the views of people with autism • Developing Services
https://www.learningforlife.com.au/our-service-models/	Learning for life centre	<p>Early Intensive Behavioural Intervention (ABA) – our Full Service Model Families already dealing with the challenges of a special needs child can find organising an ABA program overwhelming. L4Life’s Full Service Model relieves families of this burden by taking care of everything involved in establishing and running a child’s ABA program. Read more</p> <p>Early Intensive Behavioural Intervention (ABA) – our Consultancy Model For families who prefer to recruit and organise their own therapist team, but want L4Life’s expertise to design and supervise their child’s ABA program, L4Life offers the Consultancy Model. Read more</p> <p>School Behavioural Support Program (SBSP) The SBSP supports children with autism, their families and schools in integrating the children into their academic environments as successfully as possible. Read more</p> <p>Inclusion Works School Consultancy Program Distinctive for its ‘Learning by Doing’ component, Inclusion Works is an innovative educator training program designed to give teachers the independent competence to deliver effective behavioural management strategies to their current and future students with Autism, strengthening these students’ opportunity for educational success. Read more</p> <p>The Secret Agent Society Social Skills Program This revolutionary social skills program is designed to improve the emotional understanding and social skills of 8-12 year olds with high-functioning autism. Developed by the Queensland-based Social Skills Training Institute and gaining popularity worldwide, the Secret Agent Society (SAS) teaches these children crucial skills. Read more</p> <p>Autism Psychological Support Services Children with autism and their families have multiple needs. These can include the need for assessment testing and psychological reinforcement. L4Life’s team of psychologists can provide that support. Read more</p>

Organisation	Category	Summary of model
Norfolk and Suffolk Foundation Trust	Youth Team which covers young people aged 11 -18 years	If a diagnosis is made the team provides advice and support to help young people and their families to understand the diagnosis and advise them on ways that might help them manage the problems or challenges they may face at home, work or in education. The team offer clinics throughout east and west Suffolk and try to meet people as close to their home as possible. The assessments very inclusive and fully involves the young person. The website has an easy read version of the diagnostic process and there are pictures and a short summary of all the team members.
Leeds and York NHS	autism assessment service Adults over 18 yrs	https://www.leedsandYorkpft.nhs.uk/our-services/services-list/autism-diagnostic-service-lads/ The assessment offered via this service takes up to 26 weeks. The information provided in the care pathway section is easy to understand for people who are considering referring themselves to the service. The service takes self referrals.
Avon and Wiltshire	ADHD assessment service Adults over 18 yrs	http://www.awp.nhs.uk/services/specialist/bristol-adhd-clinic/ Bristol ADHD has a specialist team of doctors, psychologists, occupational therapist and nurses who work exclusively with adults who have ADHD. They receive referrals from many health professionals in the south-west and beyond. They can reassess and continue treatment of people who have a diagnosis of ADHD from childhood, and they also assess adults who have never had a diagnosis made. The information provided on the website is clear to understand.

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Bristol	BASS Autism services for adults	<p>BASS Autism Services for Adults provide a service to adults with autism spectrum conditions (ASCs) and professionals and carers who support them. There are allocated services for four geographical areas: BASS@Bristol, BASS@Bath and North East Somerset (BANES), BASS@North Somerset and BASS@South Gloucestershire.</p> <p>The service has been running in Bristol since 2009, in 2013 the two spoke services in BANES and North Somerset started and in 2014 the service started in South Gloucestershire.</p> <p>What the service provides:</p> <ul style="list-style-type: none"> • Assess and diagnose people who are referred to us by their GP. At the end of the second appointment (or in a third appointment) the service tries to give the result of their assessment. Some people may need to be seen for further appointments in order to complete the assessment. • Support colleagues in mental health services to assess and diagnose. • Social support assessments to people who have been diagnosed by the team. • Advice service with groups on mindfulness, managing anxiety, social cognition and interaction, as well as an opportunity to book one to one sessions with their staff. • Post-diagnostic support - psycho-education, coping strategies and signposting. • Training in Asperger syndrome and ASCs ranging from one hour awareness sessions to a full day's training. <p>The team do not hold a caseload or care coordinate. They currently accept referrals for people within Bristol, North Somerset, BANES and South Gloucestershire. Referrals outside of these areas can be seen on a cost per case basis, subject to funding being agreed by the referring clinical commissioning group.</p> <p>After diagnosis: After an individual receives a diagnosis of an autism spectrum condition, they are invited to attend a six week post-diagnostic support group and weekly advice service. Depending where you live, you may be eligible to attend one of the autism advice services.</p>
Durham	Durham County Council and NHS MAIN's Autism Post Diagnostic Support Service to support people aged 16+ who are resident in County Durham and have a diagnosis of an Autism Spectrum Disorder but who do not meet social care criteria.	<p>Durham County Council (DCC) and the National Health Service (NHS) jointly fund MAIN's Autism Post Diagnostic Support Service to support people aged 16+ who are resident in County Durham and have a diagnosis of an Autism Spectrum Disorder but who do not meet social care criteria.</p> <p>They aim to support adults in five key areas:</p> <ul style="list-style-type: none"> • Understanding your diagnosis, Health and wellbeing, Independent living, Accessing the community and socialising, Employment and volunteering. <p>Their Autism Resource Co-ordinators (ARC) are the first point of contact and make initial assessments and draw up care plans. Following this process our Autism resource workers (ARWs) work with service users in a 1:1 basis delivering practical support in these areas up to eight weeks per identified area of need.</p> <p>In addition under the terms of this service MAIN also provides a range of funded training courses which are available to professionals, parents and carers living/working with the above group. In the following courses:</p> <ul style="list-style-type: none"> • Awareness Training, Employing People with Autism, Identifying Autistic Traits, Understanding Care Plans, Supporting People with Autism, Challenging Behaviours and the Autism Spectrum (Promoting Positive behaviours), How to write Social Stories for people on the Autism Spectrum, Autism and Ageing: Who Cares?

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Cornwall County Council	Autism Spectrum Team – 4-16yrs	<p>The Autism Spectrum Team is a service supporting young people with autism of school age.</p> <p>The Autism Spectrum Team is an expansion of the existing Autism Services consisting of advisory teachers, specialist and highly specialist speech and language therapists, a specialist nurse practitioner, educational psychologists and Autism Spectrum Team workers. While the AS Team has a county wide brief it is organised into three area teams, West, Mid and East Cornwall, to provide a more efficient service, each of which has access to a breadth of expertise.</p> <p>Who is it for?</p> <p>The Autism Spectrum Team in Cornwall play a significant role in promoting the inclusion of young people with Autism and in supporting multi agency working to meet the needs of these young people and their families. Professionals within the Autism Spectrum Team will promote a joint problem solving approach and promote interventions that are evidence based.</p> <p>Training, Interventions and Traded Services</p> <p>Training</p> <p>Awareness Raising training - the team provide a free hour of Awareness Raising training on Autism to any school where a pupil has a diagnosis of Autism. They encourage the school to invite the broadest range of staff available (teaching staff, lunch time staff, support staff) and others, such as the SEN Governor, to this session.</p> <p>Bespoke training - training at cost to schools, settings and other professional groups, on various issues including Classroom strategies, Communication and Challenging Behaviour, Sensory Integration, Autism and Sexuality.</p> <p>Interventions</p> <p>Social Skills groups - Social Skills groups for pupils with Autism (and others with social difficulties) in secondary schools, 8 - 10 sessions, for approx 8 pupils. Cost £300.</p> <p>Autism Champions - Autism Champions is an intervention for secondary schools (usually). It involves the creation of an in-school expert on autism to provide direct support to students and advice to staff and parents. It is based on a model which has been successful in other authorities including Birmingham and Plymouth. Their first cohort of Autism Champions has recently been trained and are now embarking on this role.</p> <p>The Autism Spectrum Team consists of:</p> <p>Manager and Senior Educational Psychologist, Highly Specialised Speech and Language Therapist, Specialist Practitioner, Autism Spectrum Advisors</p> <p>When a request for involvement is made to the team they will clearly identify the objective of the involvement and then provide a tailored package using the most appropriate team members which may include:</p> <p>A range of assessments, recommendation of strategies to school staff, recommendation of strategies to parents, interventions carried out within a school, interventions carried out in the home, modelling good practice in the home/ classroom, coordination of meetings in the school setting.</p> <p>When more than one member of the team is allocated to work with a young person, their school and family, there will be regular internal professional meetings to ensure a coordinated approach to their work. The team in partnership with the family and relevant agencies will also identify when a piece of work is completed and the involvement of the team should end.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Wokingham Borough Council	ASSIST Team (Autistic Spectrum Service for Information Support and Training)	<p>The ASSIST team is part of the 0-25 Special Educational Needs and Disability Service at Wokingham Borough Council People's Directorate, based at Woodley Airfield Centre .</p> <p>The team supports children and young people with autism, people who live with them, and people who work with them from diagnosis up to their 18th birthday, and who live in the Wokingham Borough. The service can provide:</p> <ul style="list-style-type: none"> • Information, support, advice and signposting to other services • Resources such as symbols, photographs and timetables • Opportunities to meet with the ASSIST team to discuss strategies – contact the team for dates of monthly drop in sessions held at Bridges Resource Centre • Support to families to look at issues in the home environment and move towards solutions • Support to school staff to look at issues in the school environment and move towards solutions • Support to leisure providers to include children with autism • Consultation support to professionals to look at issues and solutions • Co-ordination of NAS EarlyBird, EarlyBird plus and Healthy Minds parent programmes, and the Next Steps parent programme • National Autistic Society EarlyBird, EarlyBird Plus and Healthy Minds parent programmes (overseen by NAS and managed locally by the ASSIST team) • These parent programmes are available for parents and their supporters of a child/young person with autism. Early Birds is for pre-school children, EarlyBird Plus for aged 5 – 9. The Healthy minds programme is for primary school aged children. The programmes aim to: <ul style="list-style-type: none"> • Support families • Empower parents and carers • Help families to understand their child's autism • Structure interactions in which communication can develop • Pre-empt problem behaviours and handle those that occur • The Next Steps parent programme is for parents of a young person over the age of 9 receiving a diagnosis of autism. <p>For further details of our service please view our service description (PDF)</p> <p>The ASSIST team work closely with the Wokingham Children's Autism Partnership to deliver a wide range of autism specific workshops locally. Please contact ASSIST for more information.</p> <p>Transition toolkit – generated by a group of parents and practitioners, the toolkit aims to help and support the planning of a move from one setting to another. Each transition will be unique to the child, and the toolkit promotes (as an example) best practice guidance. It includes appropriate actions for parents and carers, and the professionals involved in the current setting and the new setting.</p> <p>Referral: Via School, Self Referral, GP or other health professional, Parents or Family</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Welsh Government	Welsh integrated Autism Service	<p>The service is a national initiative and is currently under development and will be an all age service that is integrated between health and social care, to which individuals, parents and carers can self-refer in order to access timely support.</p> <p>The service includes a range of professionals including Psychologists, Speech and Language Therapists, Occupational Therapists, Specialist Practitioners and Support Workers.</p> <p>What the service provides</p> <p>Children and families</p> <p>The service supports parents and carers by providing advice, support and signposting to other services. It will also deliver programmes for young people to help manage difficulties such as:</p> <p>sleep problems; issues with eating; challenging behaviour; anxiety; developing social skills</p> <p>The integrated autism service supports autistic adults by providing advice and support, signposting to other services and delivering programmes. This includes support and advice to help manage difficulties such as:</p> <p>Anxiety; social skills; accessing leisure and recreational activities; developing daily living skills (such as paying bills, shopping and cooking); accessing other services such as healthcare or employment support.</p> <p>For those with more complex needs (where other services such as mental health support is needed), staff from the IAS will work with other professionals to ensure they are able to provide appropriate support.</p> <p>Promoting awareness, understanding and acceptance</p> <p>From their scoping work, they understand that autistic children and adults often require support to access the resources and activities that neurotypical individuals access on a regular basis.</p> <p>Autistic people want to be active members of society, access activities and engage with others and the IAS will have a pivotal role in supporting this. However community provision and wider society will need to be aware of the needs of autistic individuals and how to best support them in order for this to happen.</p> <p>The service is now operational in Cardiff and the Vale, Cwm Taf, Gwent, North Wales and Powys and will be fully operational in the remaining regions, West Wales and Western By April 2019.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Merseyside Care NHS Foundation Trust	Autism Services for Adults	<p>Liverpool Asperger Service The Liverpool Asperger team is a pioneering specialist team that provides assessment and support to working age adults within Liverpool and assessment services across the country.</p> <p>Sefton Asperger service Sefton Asperger service provides diagnosis and support for people living with Asperger Syndrome from its base at the Hesketh Centre in Southport. The service aims to provide specialist support for those people who may have previously fallen through the gaps by not being regarded as having a mental health problem or a learning disability.</p> <p>The service has a person centred care focus and uses creative interventions which help with the social and communication difficulties faced by people with Asperger syndrome, their families and care teams. Anyone aged 18 years and over may self-refer or be referred by another person for example a family member; GP or other mental health professional.</p> <p>Attention Deficit Hyperactivity Disorder (ADHD) service Sefton The adult Attention Deficit Hyperactivity Disorder service in Sefton is an award winning service that has a proven track record in providing innovative care to adults with ADHD. It serves patients transitioning to adult care from community paediatrics and CAMHS as well as providing a comprehensive assessment and diagnostic service for adults referred by their GP. The service adheres to the NICE guidance in its approach to treatment and medication is monitored by the treating clinician. They have fostered strong links locally with third sector organisations that offer additional support for families of patients with ADHD. Referral can be made via the patient's GP and following a comprehensive initial assessment, a formulation is provided. Comorbid psychiatric issues are addressed by referral to the relevant CMHT. ADHD is a complex condition and as such they recognise the importance of the initial assessment being carried out by a medical professional. They are currently supported by two consultant psychiatrists and a speciality doctor.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Manchester	Revolutionary new assessment pathway (Children) - Pilot	<p>All the services involved, together with the Manchester Parent Carer Forum, have worked together over the past several months to design a revolutionary new pathway, in a spirit of co-production which has been exemplary. The meetings have had consistent and committed representation from CAMHS (Child and Adolescent Mental Health Services), Paediatricians, Speech and Language Therapists (SLT), Occupational Therapists (OT), Health Visitors and Educational Psychologists, as well as the forum to represent parent-carers. The NHS Clinical Commissioners have agreed to fund a two year pilot of the new pathway, which will take place initially in South Manchester but will be rolled out to Central and North in due course.</p> <p>The pilot began in October 2018 for families in the South Manchester area, covered by CAMHS at the Carol Kendrick centre in Wythenshawe.</p> <p>What is changing with the new pathway?</p> <p>The new pathway requires all professionals to think and work differently together and to use resources more efficiently, placing assessment at the core of the needs of the child or young person.</p> <p>Referrals will be assessed by a core triage team of advanced clinical practitioners taken from all the services, meeting together as a group each week to look at new cases. Further information can be gathered as needed from relevant sources.</p> <p>Each referral case is assigned a named key-worker to support and inform them throughout the assessment process and assist them into the right intervention strategies. Usually this will be a clinician best suited to the child's needs – for example, SALT if their difficulties lie mainly in speech, OT for physical or sensory needs, Clinical Psychology for behaviour.</p> <p>Initial appointments will be with two clinicians, so that a developmental history can be taken from the parent-carer while the child has a clinical observation such as the ADOS. A second appointment will usually be made at the educational setting, for observation within the peer group. Parents will not be present at this observation but will be informed of the outcome.</p> <p>The new pathway formalises the assessment tools and process so that families will receive the same service no matter where they are assessed. It will also provide clear data for auditing and future planning, also undertaken with parent-carer involvement.</p> <p>The process will improve transparency and communication, making parent-carer involvement key, with a new referral form designed specifically for parent-carers. Health referrals will be streamlined, the role of education made clearer, and evidence will be gathered in detail at an early stage of the process so that assessment is not held up by lack of information.</p> <p>It takes assessment out of CAMHS and puts it into the community; autism is not a mental health problem but currently the diagnosis rests entirely in CAMHS, which can be upsetting for families and young people themselves. Some appointments will still be made at CAMHS clinics, due to resource and space allocation within the NHS, but some will now be made in local health clinics or community centres.</p> <p>All these changes should make social communication assessment much more equitable, efficient and family/child friendly and it's really an exciting and hopeful time for us Manchester parent-carers.</p> <p>Referrals are accepted from GPs, community mental health teams and paediatricians.</p> <p>What conditions does the service see?</p> <p>Children with complex developmental disorders involving social impairment. This includes autism spectrum disorder, but also problems of autism-like syndromes related to other specific genetic, neurodevelopmental, and attachment disorders.</p> <p>What treatments are offered?</p> <p>The assessment package will include a combination of the following appropriate to the case:; Family Developmental History Interview; Various symptom specific questionnaires; Structured interview for autism history; Clinical mental state examination; ADOS examination; MCAS examination; Physical examination; Psychometric Assessment; Social Cognition Tasks; Social Understanding Interview; 3DI; Speech and Language Assessment CELF; Pragmatics Assessment; Sensory Profile; ABC Movement Assessment; COSA interview; Other specific OT assessments; Handwriting assessment; Parent questionnaires and specialist interviews; Manchester Inventory Playground Observation (MIPO).</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Greater Manchester Autism Consortium		<p>The Greater Manchester Autism Consortium project is funded by the 10 councils of Greater Manchester and the 10 Clinical Commissioning Groups (local NHS organisations).</p> <p>Our work includes:</p> <ul style="list-style-type: none">• Providing information and advice to autistic people, family members and carers and professionals. This includes a website with information on the support available in different areas of Greater Manchester• Training for professionals in health and social care• Facilitating good practice sharing at events and workshops• Parent workshops for parents of children with autism under 16 on Understanding Autism, Sensory or Managing Anger.




Best Practice Assessment/diagnosis/Post diagnosis support

Organisation	Category	Summary of model
Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust	Adults	<p>In early 2017, TEWV launched a trust-wide autism project to improve its offer to autistic patients accessing mental health services. Crucial to the success of the project was strong support from the Trust's senior leadership: The Chief Operating Officer was Project Sponsor; The executive team released a sum of money (roughly £400,000 over two years); An autism strategy manager and trust-wide autism clinical lead were appointed; An expert by experience, autism nurse consultant and an administrator were recruited.</p> <p>In the first half of 2017 a series of consultation events were held with staff, service users and carers. At this point, the focus was on adult mental health services, as the Trust perceived this to be the area of greatest need.</p> <p>Some clear themes emerged from the consultation:</p> <p>The high rates of mental distress and mental illness experienced by autistic people; The difficulty accessing mainstream mental health services; The lack of staff training and understanding of autism; The long waiting times for assessment; The lack of post-diagnostic support.</p> <p>Another key theme was the importance of involving autistic people and families in a meaningful way. This became one of the Trusts guiding principles: the Trust are proud that every element of the project has had input from experts by experience,</p> <p>The TEWV autism framework</p> <p>The Trust wrote the TEWV autism framework, setting out their aims and objectives and the means by which they will achieve it.</p> <p>Their overall ambition is: Autistic people should have equal access to mental health and learning disability services, and be treated by autism-aware staff who are able to make reasonable adjustments when required. Their ambition is to be the most autism-friendly NHS organisation in the North of England.</p> <p>The key strands of work outlined in the framework are:</p> <p>Ensure autism assessment is of high quality and waiting times are reduced as much as possible; Provide staff training in autism awareness; Ensure that reasonable adjustments for autistic patients are identified and implemented; Provide consistent, high quality transitions from children and young people services to adult services.</p> <p>As well as these specific aims, the Trust also have a more overarching goal - to win hearts and minds. For too long, general mental health services have regarded autism as 'not our business'. The Trust even heard anecdotal reports of autistic people having trouble accessing mental health treatment because clinicians tell them 'we don't deal with autism'. By the end of the project, the Trust hopes that all TEWV staff appreciate that autism is their business.</p> <p>Staff training</p> <p>At the consultation events there was a strong desire from staff and service users to have a high level of training. Ultimately though they had to strike a balance between desirability and feasibility, given the resources available and the large amount of statutory and mandatory training professionals already have to complete. Finally we settled on:</p> <p>Level 1 'autism awareness' training for all staff, comprising of a 10 minute video, embedded in the mandatory Equality and Diversity elearning package. The video can be watched here.</p> <p>Level 2 'understanding autism' face to face 3 hour training package for clinical staff.</p> <p>Both level 1 and level 2 training materials were co-produced with service users. All of the face-to-face training is co-delivered with experts by experience. Although the level 2 training is not mandatory, the Trust has been heartened by the staff response. Nearly all of the sessions have been oversubscribed and feedback has been highly positive - 90 % rate the training as relevant to their role. In particular the contributions from experts by experience have been highly praised.</p> <p>As of October 2018, 635 staff have received Level 1 training and 700 staff have received Level 2 training. The aim is to train 80% of clinical staff by March 2020.</p>

Best Practice Assessment/diagnosis/Post diagnosis support

Organisation	Category	Summary of model
Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trust	Adults and children – cont.	<p>Reasonable adjustments</p> <p>The challenge here was to establish a mechanism to prompt clinicians to consider and implement reasonable adjustments as a routine part of their practice. A select group of staff, service users and carers were invited to produce a 'Clinical Link Pathway' (CLiP). A CLiP is a series of resources that are complementary to the existing TEWV standardised care pathways.</p> <p>The aim of the autism CLiP is to support clinicians in collaboratively discussing, identifying, implementing and reviewing reasonable adjustments. The CLiP resources developed so far include:</p> <p>New questionnaire for patients and carers regarding needs specific to autism; Guidance on considering the sensory environment; General hints and tips about communication; Advice on healthcare/hospital passports; Guidance around the clinical considerations for assessing and treating mental illness in autistic people. The CLiP is currently in pilot form with a plan to roll it out across all Trust localities throughout 2019. At present the CLiP only applies to adult patients, but they are planning to adapt it for children's services in due course.</p> <p>Children and young peoples' services</p> <p>The initial focus of the project was on general adult services but similar issues existed in children and young people's services (CYPS). In May 2018, additional funding was secured to expand the scope of the project, and a CYPS trust-wide professional lead and assistant were appointed.</p> <p>Currently the Trust are mapping autism assessment processes across the Trust in order to produce a gap analysis. The aim is to streamline the assessment pathway for children, including greater consistency in processes such as use of clinical tools and paperwork.</p> <p>Another priority is transitions for young autistic people (from 17.3 years) from CYPS to adult mental health/LD services, ensuring the transition protocols and procedures explicitly consider autism.</p> <p>The Trust will also establish a baseline of autism training in CYPS across the Trust with the aim of developing a comprehensive training plan. CYPS staff are being encouraged to attend the Level 2 training that is already well established in adult services.</p> <p>The future</p> <p>It is important that the project evidences clinically meaningful improvements. They are collecting a variety of outcome measures, including:</p> <p>Training analysis of numbers trained, in which teams; Staff surveys of autism knowledge and confidence in applying reasonable adjustments; Case note audit of reasonable adjustments for autistic patients; Qualitative feedback from staff on their experiences of using the autism CLiP ; Patient feedback including complaints and serious incidents.</p> <p>In September 2018 the Trust consulted on their autism strategy beyond the lifespan of the project. It was acknowledged that there is a need for ongoing staff training. Given the new national 12 week target for autism assessment waiting times, the Trust also needs to ensure their specialist autism teams are adequately resourced. There is also a need for specialist autism consultancy to work into general mental health teams for complex and high risk cases.</p> <p>All of this will require consistent levels of additional funding, but the Trust are hopeful that the prioritisation of autism in the NHS ten year plan will allow mental health trusts like theirs to invest more into autism services.</p>


Best Practice Post diagnosis support

Organisation	Category	Summary of service
Central Manchester University Hospital	Recognising Autism management Programme (RAMP) Childrens	<p>Programme designed to improve access to Acute and urgent care services for children with autism</p> <div>  <p>Adobe Acrobat Document</p> </div> <div>  <p>Adobe Acrobat Document</p> </div> <div>  <p>Adobe Acrobat Document</p> </div>
Cambridge & Peterborough NHS Trust	Neurodevelopmental Service (NDS) - integrated multi-agency service for school-age children and young people with known or presumed neurodevelopmental difficulties. Childrens	<p>After an initial review of referral information and then a General Developmental Assessment (GDA) by a community paediatrician, children and young people may be referred to one of their specialist integrated multi-agency teams that focus on:</p> <ul style="list-style-type: none"> •Attention deficit hyperactivity disorder (ADHD) •Autism spectrum disorder (autism) •Children's learning disability and associated mental health team (the Children's Learning Disability Team) •Also hold a Tourette's Syndrome clinic. <p>They help school age children and young people, their families and professionals involved with them through consultation, assessment, diagnosis, interventions, monitoring, review and training which includes:</p> <ul style="list-style-type: none"> •Clinic appointments •Home visits •Psycho-education groups •Educational liaison •Other child and parent training as appropriate

Best Practice Post diagnosis support

Organisation	Category	Summary of service
Norfolk Community Health & Care Trust	Starfish ADHD Nursing Service Childrens	Works with children who have been diagnosed with an attention deficit disorder or are going through an initial assessment of a suspected attention deficit disorder. Set clinic days: <ul style="list-style-type: none">• Initial triage to determine if Paediatric input is required• Supporting diagnosis through observation at school or at home• Parent information workshops after a child has been diagnosed• Medication review/follow-up• Behavioural interventions
Luton Borough Council	Autism Support Service Childrens	Specialist service which works with 3-16 year olds with a diagnosis of autism spectrum disorder. They offer advice and support for parents, carers and schools and accept referrals from a range of professionals in consultation with the family. Team consists of two Advisory Teachers for pupils aged between 7-16 years and two Advisors for the Early Years aged between 3-7 years.

Best Practice Post diagnosis support

Organisation	Category	Summary of service
Devon's Integrated Children's Services – Virgin Care	Autism Spectrum Assessment Service Childrens	<p>The Autism Spectrum Assessment Service provides diagnosis and help for children and young people up to 18 years of age suspected of being on the Autism Spectrum.</p> <p>http://devon.integratedchildrensservices.co.uk/wp-content/uploads/2017/01/WEB-Devon_Austism_Assessment_A5_booklet_03.01.16-EC.pdf</p>
Norfolk – County Council & CCG	Children & Young People Pathway	 <p>Adobe Acrobat Document</p>
Northumberland, Tyne and Wear NHS Foundation Trust	The Complex Neurodevelopmental Disorders Service (CNDS) is a specialist tertiary second opinion Autism Spectrum Disorder (autism) service for children and young people Childrens	<p>Nationally commissioned by NHS England CNDS works in collaboration with locality teams. In addition to autism diagnostic assessments the team also provides consultation and management advice to locality teams for complex cases with established autism diagnoses.</p> <p>CNDS provides the new Blue Room Treatment for situation specific anxiety, phobia and fear in children with autism. The following brochure has been written to give families and professionals information about this novel treatment.</p> <p>Referrals for treatment are accepted via Community CAMHS team, Community Paediatrician or GP.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of service
South London & Maudsley Hospital	Service for Complex Autism & Associated Neurodevelopmental Disorders – National Service Childrens	The SCAAND service is commissioned by NHS England and it is a requirement that all referrals have been through a local assessment/care pathway for autism before referrals can be accepted. The 3 Teams, which work as one service and are multidisciplinary, are able to ensure that the needs of the child and their family are assessed and managed in a comprehensive manner. SCAAND aims to work with local services as flexibly as possibly.
Leicestershire partnership Trust	Children's' service and transition service Childrens	Full range of pathways here: http://www.leicspart.nhs.uk/OurServicesAZ-AutismCarePathway.aspx

Best Practice Post diagnosis support

Organisation	Category	Summary of service
Devon Partnership Trust	Devon Adult Autism and ADHD (DAANA)	Signposting pack available online Also provides training to trust staff to enable them to make their services accessible for those with autism/ADHD. Provides a diagnostic and advisory role for the assessment of high functioning autism/Asperger's disorder and Attention Deficit Hyperactivity Disorder (ADHD) for adults only.
South London and Maudsley SLaM	ADHD and autism services Also provides the National Autism unit Adults	SLaM have over 25 years experience in the diagnosis and management of adults with Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (autism), who have co-morbid mental health difficulties and offending or challenging behaviour. They provide in-depth assessments and effective, evidence-based, patient-centred treatments to people across the UK. ADHD diagnosis, autism diagnosis, Neurodevelopmental disorders, ADHD medication, Adapted psychological interventions, autism and other co-morbid mental health difficulties.
North Yorkshire Autism & ADHD Assessment Service	The Tuke Centre Adults	The Tuke Centre has been contracted by four Clinical Commissioning Groups (CCGs) across North Yorkshire to provide an Autism and ADHD Assessment Service, free at the point of delivery. The service covers the following CCG areas: <ul style="list-style-type: none"> •NHS Vale of York CCG •NHS Harrogate and Rural District CCG •NHS Hambleton, Richmondshire and Whitby CCG •NHS Scarborough and Ryedale CCG Screening for Autism Spectrum Disorder (autism) Assessment and diagnosis of autism Screening for Attention Deficit and Hyperactivity Disorder (ADHD) Assessment and diagnosis of ADHD A limited number of sessions to help you make sense of your diagnosis

Best Practice Post diagnosis support

Organisation	Category	Summary of model
National Autistic Society (NAS)	Online support to help diagnose autistic women and girls	<p>Launched in March 2018 - Online support to help diagnose autistic women and girls. The aim of the Women and Girls on the Autism Spectrum module is to support professionals to identify autism in women and girls. It is specifically aimed at diagnosticians, but has been developed in such a way that it should be useful to anyone with an interest in autism, including autistic people, parents, carers and a wide range of other professionals. It is now recognised from research, clinical practice and anecdotal reports that many undiagnosed autistic females, or those who demonstrate the less traditionally obvious traits of autism, are not recognised. This can result in misdiagnosis, late diagnosis, or those individuals not being diagnosed at all.</p> <p>This module aims to provide an insight into the potential differences experienced by autistic women and girls. The philosophy of all our online modules is to put the autistic voice at the centre.</p> <p>While managed by the National Autistic Society, this project is being overseen by the National Association of Head Teachers (NAHT) Autism and Girls forum. The forum is an external reference group which was formed to raise awareness of autism in women and girls. The group consists of key people in the field of autism, including researchers, autistic women, education professionals, academics, parents of autistic girls and senior staff from the National Autistic Society.</p> <p>The NAS wanted the module to be interactive in order to make the learning process more engaging, and so they worked with a company called Little Man Project to explore what the key principles were and the messages that they needed the module to get across. Little Man Project pulled this together and have built an interactive module.</p> <p>The module will enable professionals to review the potential differences that autistic women and girls might experience from non-autistic females, and from autistic boys and men. The module looks at the historical perspective to try and understand why they may have been missed in the past, and focus on developmental characteristics that you might be able to observe in someone (or yourself).</p> <p>The module includes several film clips with autistic women and clinicians, giving further insight into different autistic perspectives and advice for clinicians from clinicians. A useful addition are several examples of questions to ask or things to observe, which can all be added to a folder to download at print at the end.</p> <p>This module has been developed in conjunction with autistic women and leading clinicians. Contributors have included the focus group of autistic women, autistic content writers including Lana Grant, Sarah Hendrickx and Dr Wenn Lawson, and clinicians including Dr Judith Gould.</p> <p>The aim is to ensure that more autistic women and girls are recognised and diagnosed, enabling them to gain access to the support and understanding they are entitled to. The impact of the project will be measured through a variety of ways, including collating feedback from those who have completed the module and working with professionals and individuals to examine whether more women and girls are diagnosed.</p> <p>One of the most important learning points that it is hoped people will take from the module is the importance of listening to what autistic girls are telling us and why diagnosis can be so vital in terms of self-esteem, being able to understand yourself and being supported in the right way.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
National Autistic Society Centres	Day services for adults	<p>The National Autistic Society (NAS) have developed a new range of support for autistic adults to replace their existing day services. Following extensive consultation NAS amended all NAS day services to The National Autistic Society Centres. All Centres have a standard way of operating for greater consistency in provision. This ensures a quality standard that can be monitored against and across all services.</p> <p>What the Centres' offer</p> <p>Extended opening hours to enable autistic adults to find support at the times they require it. The Centres aim to extend their reach to include all autistic adults, particularly those who before now have been unable to find a service which meets their needs. The Centres also aim to ensure that services are designed around the individual needs of the people they support and that they decide which areas of their lives our support focuses on. To ensure this they have intrinsically linked three key approaches.</p> <p>Outcomes Framework</p> <p>The Outcomes framework enables a person they support to identify and develop their own Personalised Outcomes Plan, which identifies what an individual wants to achieve through their support, and sets out how this will be achieved. The Outcomes Framework then sets out the documentation which supports the measuring, evidencing and monitoring of an individual's outcomes, and provides the rationale behind the modules an individual is participating in during the Modular Learning Programme.</p> <p>Module Framework</p> <p>The Module Framework (used within the Modular Learning Programme) sets out the documentation which supports our staff in delivering modules/sessions effectively and, through linking with the Outcomes Framework, ensures the sessions we deliver directly link to the individuals personal outcomes.</p> <p>The modules we offer cover a range of subjects such as Travel Training, Communication, Art, Employment Skills, Sensory and many others which support autistic adults in a variety of ways such as budgeting, planning, flexible thinking and social communication. The sessions within each module are written to meet the needs of the individual and to support them in working toward their outcomes.</p> <p>Support Plans</p> <p>Personal Support Plans identify and record the areas in which an individual needs support, the way in which they would like the support provided to them and how that support is delivered in practice. Support plans feed into and inform the development of personalised outcomes plans.</p> <p>By linking these together we ensure our values and approaches are consistent across all Centres.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
National Autistic Society Centres	Day services for adults cont:	<p>Services for autistic adults</p> <p>1. Breakfast Club Their Breakfast Club enables family members to bring people they support to the Centre on their way to work. Staff support individuals to prepare their own breakfast and to eat together in a social and supportive environment. This service is particularly beneficial to people we support who need the time to transition into our Modular Learning Programme which takes place during traditional “day service” hours, starting at 9 or 9.30am. By opening our Centres earlier to incorporate this service they can meet the individual needs of people they support.</p> <p>2. Modular Learning Programme Their Modular Learning Programme uses the traditional “day service” hours to provide an outcome-led service which meets the specific needs of each person they support. This is achieved through the development of the Personalised Outcomes Plan, which is used alongside the individual’s Personal Support Plan to identify specific modules best suited in supporting them. This offers each person they support a day of meaningful and beneficial module sessions.</p> <p>3. Supper Club The Supper Club is an extension of our Modular Learning Programme. Staff support individuals to prepare a light meal and to eat together in a social and supportive environment. This is particularly beneficial to family members who may need more time before collecting people we support after work.</p> <p>4. Evening Groups The Evening Groups can be accessed by all autistic adults in the community. Evening Groups are held in two hour sessions which are operated by support staff and where the content is chosen by the autistic adults who attend them. Depending on what needs are identified in the area, evening groups may consist of sessions such as: social groups, short-term courses, family support groups, quiz nights, fitness and exercise groups, and drama groups etc.</p> <p>5. 1:1 Support Sessions The 1:1 Support Sessions are also available during the Centres opening hours and at times which meet the needs of an individual. This means that autistic adults who are in employment or who are at university have the opportunity to still access support. It also means that support can be focused around their specific needs and provided by a staff member with the specific knowledge base in the required area of support. Sessions are booked in 1 or 2 hour slots in advance of the session.</p> <p>6. Weekend Day experiences On weekends they support people to pursue their interests and hobbies by going on a range of trips and visits. These might include trips to the seaside, walks in the country, visits to museums/theatres/cinemas, boat trips, steam train rides etc. A programme of events can be planned with the people we support on the day out. The services offered at The National Autistic Society Centres are designed to be flexible and are offered at different days and times according to the needs of the people they support.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Cork Association for Autism	Aspect Asperger Syndrome Support Service - One Stop Shop for Adults	<p>Aspect provides specialist support and intervention to approximately 300 adults in the Cork and Kerry area while also promoting awareness, education and understanding of Asperger Syndrome.</p> <p>Aspect is a support service developed specifically for adults with Asperger Syndrome/ High Functioning Autism. Asperger Syndrome is a spectrum condition which can present in many different ways and to varying degrees. It commonly effects social communication, social interaction, social imagination and sensory processing. Characteristics of Asperger Syndrome can vary from person to person and as with everyone, personal patterns and challenges alter and develop with experience and maturity. Because of this, the key workers at Aspect strive to provide a wide range of services to best suit their client's needs.</p> <p>Aspect clients liaise with qualified and experienced key workers who help provide information and guidance in the areas of:</p> <ul style="list-style-type: none"> • Education • Employment • Independent living skills • Communication and social skills • Sensory sensitivities • Social and community involvement • Leisure and recreation <p>Those engaging also have access to various Aspect services and groups that are facilitated by the team. These services include:</p> <ul style="list-style-type: none"> • Counselling • Social/communication skills training • Training courses, workshops, seminars • Sensory integration interventions • Social groups • Regular social outings • Leisure and outdoor activities • Client and relatives support meetings <p>Links with housing authorities, local universities, employment agencies, etc. have been established by key workers to provide well informed and productive advice. There are also supports for relatives through Group Meetings which provide access to information and guest speakers with expertise in related areas. Contact us on the below details for more information and to request an Aspect application form.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
The Centre for Autism and Developmental Disabilities in Pennsylvania.	Multi-disciplinary support across all ages	<p>The health home model is a model for individuals with autism or ID in a specialty behavioural health setting, with a multidisciplinary team that has expertise in treating these conditions. A lifelong and developmentally focused approach to the behavioural health needs of these at-risk populations may provide the greatest opportunity for maximising independent functioning, sustaining family health, and optimizing medical care. Such a model would serve as a regional comprehensive treatment centre where patients with autism or ID (and their families) would be evaluated and receive evidence-based care and guidance over the lifespan of the family member. Furthermore, such a health home would encourage families to focus their already stretched resources on maximizing the developmental progress of the disabled family member, rather than struggling to manage the silos of care in the current system. Overall, the health home works to ensure that community resources are carefully coordinated and follow best practices to optimize both individual and population-level health.</p> <p>Philhaven Behavioural Health is the 13th largest behavioural U.S. health provider. The Centre for Autism and Developmental Disabilities (CADD) is a Philhaven program that serves as the central Pennsylvania regional centre for autism and ID. CADD is developing an integrated health care approach for individuals with autism or ID that is based on the health home model. CADD has a multidisciplinary team with recognised expertise in the treatment of the social, emotional, and behavioral issues affecting individuals with autism or ID. Currently, team members' backgrounds at CADD include psychiatry, nursing, psychology, behaviour analysis, social work, and counselling. Principles of the CCM have driven the philosophy of the program since its inception in 2005. Patients and families are engaged in an active partnership that involves evidence-based care delivered by a coordinated practice team. CADD provides ongoing care to approximately 1,200 individuals with autism or ID and their families. CADD treats patients over the lifespan; patients' ages range from 12 months to 65 years and older. CADD completes approximately 500 multidisciplinary evaluations per year and provides both office-based and community-based services.</p> <p>However, notable gaps exist in the full implementation of the health home model. Current third-party reimbursements do not support the life-care manager position, which is critical for true integration of care. Funding streams must offer greater flexibility to support innovative health care solutions for high-risk populations. In addition, although the model at CADD arguably has merit, the program has yet to integrate outcomes research into the clinical operations to determine the clinical effectiveness and cost-effectiveness of this coordinated system of care for patients with autism and ID.</p>

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Autism Spectrum Australia (Aspect)	Support across all ages	<p>Aspect is the one of the largest providers of disability services in the Australia, with eight schools and services for children, teenagers, adults, families and carers and professionals, helping more than 10,000 people with autism or other disabilities and their families every year.</p> <p>Service provides include:</p> <ul style="list-style-type: none">Assessment across the life spanEarly interventions:Aspect building blocks TM involves parents and their child attending a series of structured group sessions across the year. Children attend a highly structured, small group where they participate in indoor play, outdoor play, circle time and snack time.™Individual therapy servicesWorkshopsOther programmesEducational outreachPositive behaviour support <p>Aspect Choose & Connect works to individual interests to give people the confidence and skills to live successfully on their own terms and enjoy activities and connections within their local community.</p> <ul style="list-style-type: none">Adult social groupsPost schools programmes <p>We belong is an Australian first study which investigates the life experiences, aspirations and service and support needs of these Australian adults.</p> <ul style="list-style-type: none">Aspect capable employment serviceClub weld – a variety of music programmesDay centres ad respite

Best Practice Post diagnosis support

Organisation	Category	Summary of model
Explore specialist advice - New Zealand	Education services for families of children and young people who have Autism Spectrum Disorder	<p>18 October 2017 – EXPLORE SPECIALIST Advice (Explore) took over the national contract for education services for families of children and young people who have Autism Spectrum Disorder (autism) earlier this year.</p> <p>As well as providing autism services, Explore is the national provider of behaviour support services for people with disabilities who experience challenging behaviour. Explore prides itself on providing quality, flexible services and educational programmes that are based on positive support frameworks and evidence-based best practice.</p> <p>Its services and programmes are delivered by registered health professionals, including psychologists, occupational therapists, speech language therapists, social workers and other behaviour specialists with experience in the sector.</p> <p>Explore's autism programmes</p> <p>Programmes are arranged into three levels to suit the specific needs of a family / caregiver who has a child with autism. The levels provide a clear needs-based pathway, <i>from Parent Education and Support</i> to intense <i>Behaviour Support</i> services.</p> <p>All programmes are flexible to meet the specific needs of each family, are based on best practice and on New Zealand's autism guidelines, and are provided free of charge throughout New Zealand, including in rural and remote locations.</p> <p>Level 1: Parent Education and Support:</p> <ul style="list-style-type: none"> •autism+ programme (under 7 years) •The autism+ programme is for parents and caregivers who have children recently diagnosed with autism. •It is designed to increase parent/caregiver knowledge about common challenges children with autism face such as communication, behaviour, stress and learning styles. •The programme helps parents/caregivers identify ways of supporting a child with these challenges. autism+ includes seven modules that can be delivered in a group session or individually. You can also access the autism+ programme remotely. <p>Parents can refer themselves to this programme by contacting Explore to make a direct referral (0800 000 421), or by contacting your autism Coordinator, Health Professional within Child Development Services, Early Childhood Education Services or your NASC Coordinator.</p> <p>Level 2: Targeted Parent Support</p> <p>The Targeted Parent Support programme aims to strengthen parents/caregivers' skills to manage specific difficulties their child may be experiencing as a result of autism.</p> <p>Working with an Explore specialist, parents/caregivers learn skills to manage their child's particular challenges such as social communication, understanding relationships, understanding strong emotions, coping with change, managing sensory sensitivities, everyday activities and routines like mealtimes, sleep and toileting.</p> <p>For a referral to this programme contact your autism Coordinator, Paediatrician within Child Health Service, a qualified professional (psychologist, psychiatrist with autism experience and expertise) or your NASC Coordinator.</p> <p>Level 3: Behaviour Support Services</p> <p>Behaviour Support services are tailored to a child/young person's individual needs where their challenging behaviour has a significant impact on their life.</p> <p>Working with an Explore specialist, parents/caregivers will learn skills to help reduce the impact of the challenging behaviour.</p>

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New Zealand	Needs assessment co-ordination organisation	<p>Autism spectrum disorder support</p> <p>Nationally people with autism spectrum disorder (autism) can access a range of disability support services to enable them to live everyday lives and to connect with the wider community.</p> <p>The package of disability support services is determined according to the person's identified individual disability support needs by a Needs Assessment Services Coordination (NASC) organisation. Disability supports are funded by Disability Support Services in the Ministry of Health.</p> <p>Support services for people with autism</p> <p>The following autism-specific support services are available:</p> <ul style="list-style-type: none"> • autism-specific Disability Information and Advisory Services (DIAS) • autism parent education (autism Plus, TIPS for Autism, Growing up with Autism) • autism Communication and Behaviour Support • autism Developmental Coordination. <p>There is also a range of other disability support services which include such services as home and community supports, supported living, respite and carer support.</p> <p>Accessing disability support services</p> <p>People with autism may be eligible for disability support services and can contact their local NASC organisation. The NASC will undertake a needs assessment to determine what disability-related needs a person may have. The NASC may then allocate disability supports to meet the identified disability-related needs.</p> <p>Eligibility criteria is nationally consistent</p> <p>Disability Support Services (DSS) has developed a clear, nationally consistent approach to accessing disability support services for people with autism. From 2 April 2014:</p> <ul style="list-style-type: none"> • people with a sole diagnosis of autism as well as people with autism and another co-existing physical, intellectual or sensory disability can access disability supports through DSS • people who currently access disability support services will have no change to their level of support.



Improving health and wellbeing

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