

# Waiting times for assessment and support for neurodevelopmental conditions

Annex to the main report

October 2024







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### **Overview**

This annex contains additional analysis of previously unpublished data from NHS England's Mental Health Services Data Set (MHSDS)<sup>1</sup> and unpublished data from the Community Services Data Set (CSDS). It should be read in conjunction with the main report "Waiting times for assessment and support for autism, ADHD and other neurodevelopmental conditions", which includes a methodology section.

This document contains further breakdowns of waiting times for community health services by:

- Children's outcomes (referral closed, had contact, still waiting) by ICB level;
- Waiting time for diagnosis by geography ICB level.

As well as further breakdowns of waiting times for mental health services by:

- Autism-specific services;
- Waiting time for first appointment by geography;
- Waiting time for first appointment by age;
- Waiting time for first appointment by gender;
- Waiting time for first appointment by ethnicity.

<sup>&</sup>lt;sup>1</sup> MHSDS data sent by NHS England to the Children's Commissioner's office is subsequently published on NHS England's website. Some Community Services Data Set (CSDS) data presented in this report is publicly available.



# Additional analysis from the Community Services Data Set (CSDS)

### Outcomes for children in community health services – by geography

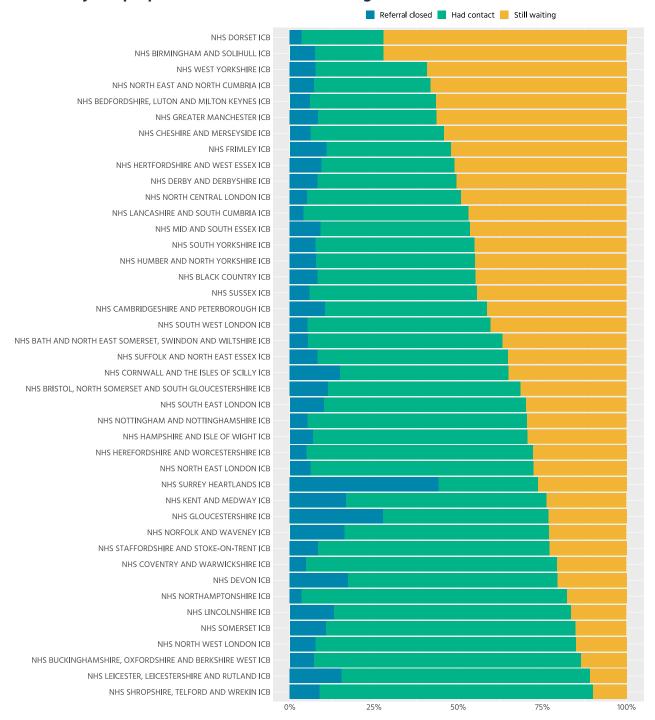
There is a large postcode lottery regarding outcomes for children by ICB (Figure A1). The percentage of children referred to community services in 2022/23 for services eventually linked to NDD diagnosis who had contact with NHS services within the financial year ranged from 81% in NHS Shropshire, Telford and Wrekin to 20% in NHS Birmingham and Solihull.

Generally, areas with a low proportion of children receiving their first contact also have a high proportion of children still waiting. Proportions of children still waiting ranged from 72% in NHS Dorset and NHS Birmingham and Solihull to 10% in NHS Shropshire, Telford and Wrekin.

However, some areas have a particularly high rate of children whose referrals were closed before treatment. The highest rate was found in NHS Surrey Heartlands where almost half (44%) of children referred had their referrals closed, followed by NHS Gloucestershire with 28%. The areas with the lowest proportion of children with referrals closed before treatment was NHS Dorset and NHS Northamptonshire, with 3.4% and 3.5% respectively. However, while the majority of children in NHS Dorset were still waiting (72%), most children in NHS Northamptonshire received their first contact (79% receiving their first contact), 18% still waiting).



Figure A1. Outcomes of children referred to community services in or before 2022-23 for services associated with eventual NDD diagnosis in 2022-23 and 2023-24 by Integrated Care Board, ordered by the proportion of children still waiting



Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data



The services with the largest proportion of children who have received one contact are Speech and Language Therapy Service (70%), Physiotherapy Service (68%) and Health Visiting Service (66%). The services with the smallest proportion of children receiving a contact were the School Nursing Service (24%) and the Vulnerable Children's Service (31%).

The Family support service (37%) and the long-term conditions case management service (29%) had the largest proportion of children whose referrals were closed before treatment. The Health Visiting (6%), School Nursing (6.8%) and Speech and Language Therapy (9.5%) services had the smallest proportion of children with their referrals closed.

### Waiting times for NDD diagnosis by geography in community health services – by ICB level

In 2022-23 and 2023-24, South East London ICB had the highest number and proportion of children diagnosed with any NDD (7,820 children, 22%) followed by Hertfordshire and West Essex ICB with 5,990 (17%) and Cheshire and Merseyside ICB with 4,040 (11%) – see Table A1 which contains unrounded figures).

Table A1. Number and percentage of children who received a diagnosis in 2022-23 and 2023-24 by ICB.

ICB	Number of children with a diagnosis	Percentage of children with a diagnosis (%)
NHS South East London ICB	7,821	22%
NHS Hertfordshire and West Essex ICB	5,988	17%
NHS Cheshire and Merseyside ICB	4,043	11%
NHS North East and North Cumbria ICB	3,019	8.6%
NHS Bath and North East Somerset, Swindon and Wiltshire	2,244	6.4%
ICB		
NHS Sussex ICB	2,065	5.8%
NHS North East London ICB	1,741	4.9%



NHS South Yorkshire ICB         1,307         3.7%           NHS Suffolk and North East Essex ICB         1,260         3.6%           NHS Hampshire and Isle Of Wight ICB         823         2.3%           NHS Humber and North Yorkshire ICB         776         2.2%           NHS West Yorkshire ICB         588         1.7%           NHS Derby and Derbyshire ICB         283         0.8%           NHS Cambridgeshire and Peterborough ICB         259         0.7%           NHS Gloucestershire ICB         231         0.7%           NHS Staffordshire and Stoke-On-Trent ICB         214         0.6%           NHS Devon ICB         202         0.6%           NHS Coventry and Warwickshire ICB         125         0.4%           NHS Kent and Medway ICB         119         0.3%           NHS Nottingham and Nottinghamshire ICB         95         0.3%           NHS Lincolnshire ICB         78         0.2%           NHS Buckinghamshire, Oxfordshire and Berkshire West ICB         53         0.2%           NHS Birmingham and Solihull ICB         36         0.1%           NHS Mid and South Essex ICB         33         0.1%           NHS Bedfordshire, Luton and Milton Keynes ICB         33         0.1%           NHS Nortfolk and Wav	NHS Greater Manchester ICB	1,669	4.7%
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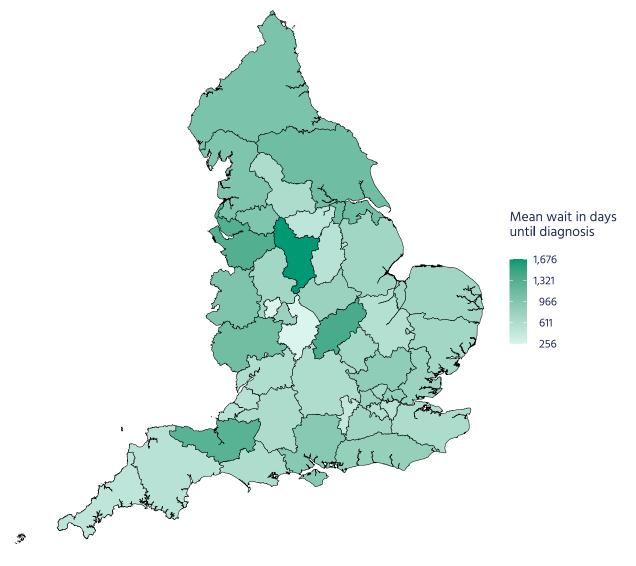
Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data Note: the Children's Commissioner's office is aware of data quality issues in some local areas.

How long children wait from referral to diagnosis varies widely by local area (Figure A2). The ICBs with the shortest waiting times are NHS Black Country ICB (average of 256 days or 8 months), NHS Coventry and Warwickshire ICB (average of 257 days or 8 months) and NHS South Yorkshire ICB (average of 486



days or 1 year and 4 months). The ICBs with the longest waiting times are NHS Derby and Derbyshire ICB (average 1,676 days or 4 years and 7 months), NHS Northamptonshire ICB (average 1,399 days or 3 years and 10 months) and NHS Cheshire and Merseyside ICB (average 1,331 days or 3 years and 8 months).

Figure A2. Map of average waiting time in days from referral in or before the 2022-23 financial year until diagnosis in 2022-23 and 2023-24 with a neurodevelopmental disorder, by Integrated Care Board.



Source: Children's Commissioner's office analysis of unpublished Community Services Data Set data Note: the Children's Commissioner's office is aware of data quality issues in some local areas.



## Additional analysis from the Mental Health Services Data Set (CSDS)

### Waiting times for autism services in in mental health services

A total of 47,300 children were referred in or before the 2022-23 financial year for autism related reasons - 43,700 for suspected autism and 3,600 for diagnosed autism. Of these, 13,300 (28%) children received a contact - 11,300 for suspected autism and 2,000 for diagnosed autism.

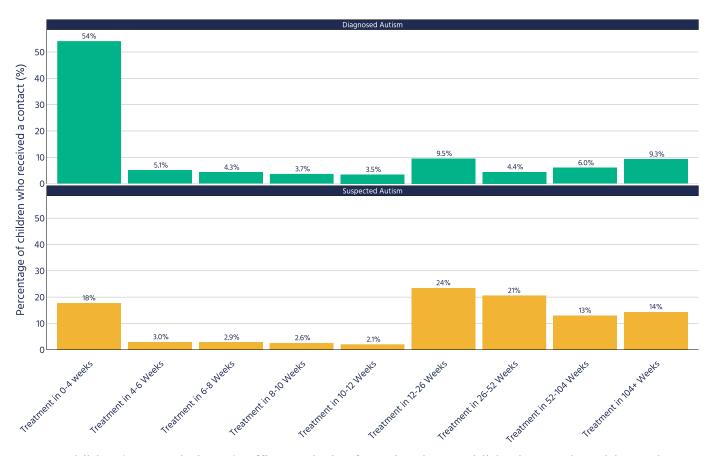
Another 24,500 children (52%) were still waiting for their first contact - 23,400 for suspected autism (likely for assessment) and 1,200 for diagnosed autism, which could include referrals to a number of different services including behavioural or mental health support. 9,430 (20%) children had their referrals closed before their first contact, 8,980 for suspected autism and 450 for diagnosed autism.

For those who received a contact with suspected autism as their primary referral reason, they waited a median of 5 and a half months (168 days) or a mean wait of 10 months (296 days) until their first contact with CYPMHS learning disability and autism services. For those whose referral reason was diagnosed autism, they waited a median of 20 days or a mean wait of 7 months (212 days) until their first contact. This disparity between median and mean waits, suggests that some children are waiting particularly long periods of time, which has pulled up the mean substantially.

Overall, children with diagnosed autism received a contact faster than those with suspected autism (see Figure A3). Over half (54%) of those with diagnosed autism received a contact within a month (4 weeks) while only 18% of those with suspected autism did so. In fact, 27% of those with suspected autism received a contact after waiting a year (52 weeks) – 14% of which received a contact after waiting over 2 years (104 weeks). This is likely due to how those with diagnosed autism were not referred for assessment and diagnosis but for support for their autism which was already diagnosed.



Figure A3. Time taken for children to receive a contact with CYPMHS learning disability and autism services in 2022-23 where their referral reason was diagnosed or suspected autism.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services data

Those still waiting with the referral reason of 'suspected autism' have been waiting a median of over 7 months (225 days) or a mean wait of 11 months (332 days). Those still waiting due to 'diagnosed autism' have been waiting a median of 8 months (247 days) or a mean wait of a year and 1 month (404 days).

#### Waiting times from referral to first contact for children accessing "Autism service"

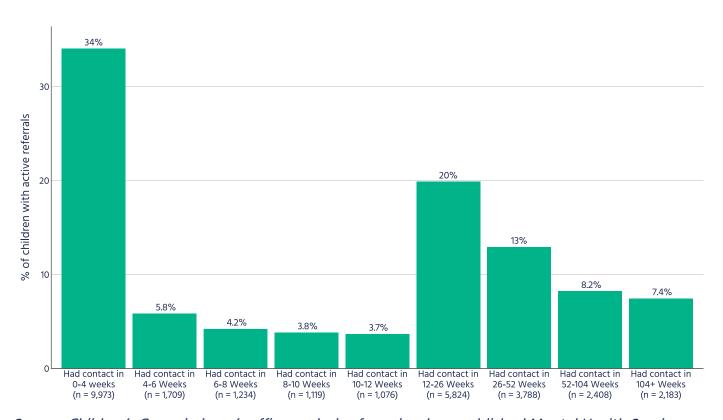
In 2022-23, a total of 55,400 children were referred to the Autism Service. Of these, 17,200 (31%) children had their first contact, 26,000 (47%) were still waiting for their first contact and 12,100 children (22%) had their referrals closed before treatment.



For those who were referred to the Autism Service and successfully had their first contact, they waited a median of 4 and a half months (139 days) or had a mean wait of over 8 months (256 days) until their first contact. For those still waiting to access the Autism Service, they had been waiting a median of over 6 months (196 days) or a mean of almost 11 months (324 days).

Some children made contact with autism services quickly, with a fifth (22%) receiving their first contact with within a month (see Figure A4). However, another fifth (22%) received their first contact after waiting over a year (52 weeks) – 11% of whom were waiting over 2 years (104 weeks).

Figure A4. Waiting time from referral in or before the 2022-23 financial year to first contact with CYPMHS Autism Service in 2022-23.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services data



### Differences in waiting times for mental health services by children's characteristics and circumstances

### Differences in waiting times for mental health services by geography

Note: This section presents MHSDS data on numbers of children with learning disabilities and/or autism referred to CYPMH services and waiting times by geography, at both regional and ICB level. As with the CSDS, not all providers submit data to the MHSDS and submitted data may vary in completeness.

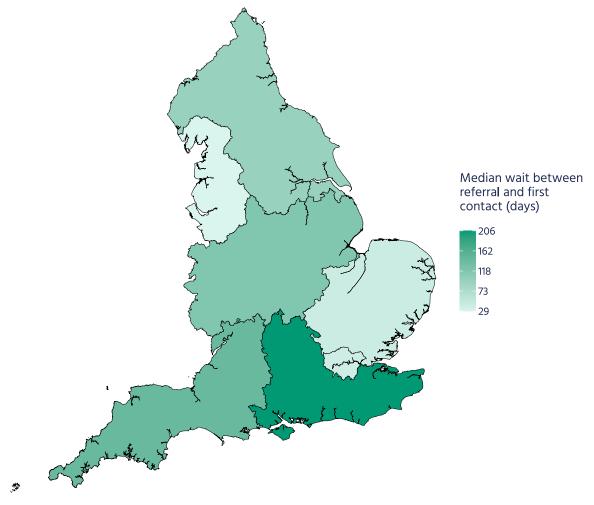
### Region

In 2022-23, the Midlands had the highest number and proportion of children referred for LDA services (21,900, 27%), followed by South East with 15,200 (19%) children and North West with 12,800 (16%) children.

The regions with the longest waiting times are the South East (median 206 days or mean 358 days), South West (median 143 days or mean 296 days) and Midlands (median 119 days or mean 241). The regions with the shortest waiting times (all about a month) are the North West (median 29 days or mean 101 days), London (median 42 days or mean 120 days) and East of England (median 45 days or mean 196) – see Figure A5).



Figure A5. Median waiting time in days from referral in or before the 2022-23 financial year to receiving a contact with CYPMHS learning disability and autism services, by region.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data

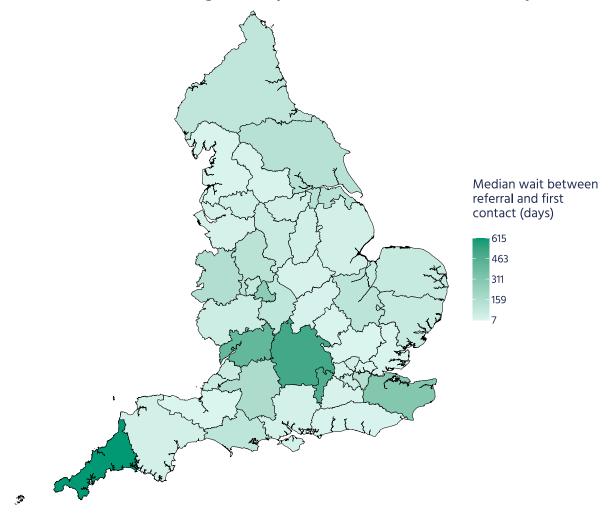
#### **ICBs**

Greater Manchester had the highest number and proportion of children referred for LDA services (7,090, 8.8%), followed by Kent and Medway with 6,930 (8.6%) children and Birmingham and Solihull with 6,850 (8.5%) children.



The ICBs with the longest waiting times are Cornwall and the Isles of Scilly (median 615 days or mean 524 days), Buckinghamshire, Oxfordshire and Berkshire West (median 512 days or mean 472 days) and Frimley (median 470 days or mean 444 days) – see Figure A6 below. The ICBs with the shortest waiting times are Somerset, Hertfordshire and West Essex and Lancashire/South Cumbria with median waits of 7, 8 and 10 days (mean waits of 120, 291, 90 days) respectively. The office is aware of data quality issues in some local areas which mean these numbers may not reflect the reality on the ground.

Figure A6. Median waiting time in days from referral in or before the 2022-23 financial year to receiving a contact with CYPMHS learning disability and autism services in 2022-23, by ICB level.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data



### Differences in waiting times for mental health services by age

Children aged 0 to 4 were the largest group of children accessing CYPMHS learning disability and autism (LDA) services, making up 23% of all receiving a contact – just under the proportion of children aged 0 to 4 in the England population (26%) – see Table A2. Over half (55%) of all children and young people who received a contact with LDA services were under 10 years old. Waiting times were longest for the youngest children (median 116 days or mean 276 days) and get shorter with age (see Figure A7 below).

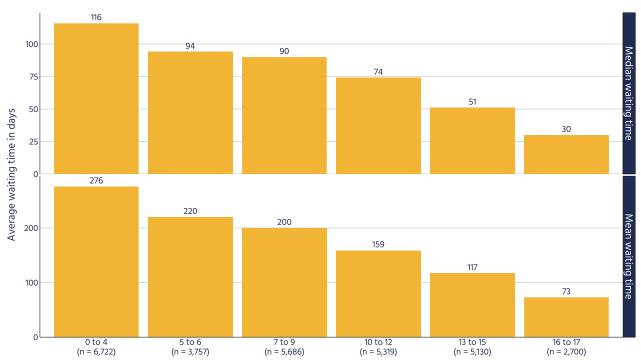
Table A2. Waiting times from referral in or before the 2022-23 financial year to 1st contact with services in 2022-23 for children and young people with an active referral, by age group.

Age group	Number of children referred	Percentage	Median waiting time in days	Mean waiting time in days
0 to 4	6,722	23%	116	276
5 to 6	3,757	13%	94	220
7 to 9	5,686	19%	90	200
10 to 12	5,319	18%	74	159
13 to 15	5,130	18%	51	117
16 to 17	2,700	9.2%	30	73
All ages	29,314	100%	74	187

Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data



Figure A7: Waiting times in days from referral in or before 2022-23 to their first contact with CYPMHS learning disability and autism services in 2022-23, by age group.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data

### Differences in waiting times for mental health services by gender

In 2022-23, almost two-thirds (63%) of children receiving a contact with services were boys, compared to 36% girls and less than 1% of children who were either non-binary or unknown (see Table A3). This is similar to our findings on community services data where 70% of children with any NDD diagnosis were boys. This is consistent with wider research which shows that male children are up to four times more likely to be diagnosed than female children. As has been highlighted throughout the main report, while some of the differences in diagnostic rates between boys and girls can be attributed to genetic and sex hormone differences, there is a growing body of research which indicates that the disparity in diagnostic rates is exaggerated by biases in the perception, assessment and diagnosis – particularly for autism and ADHD.



Similarly to the trend we see in community health services (with boys waiting longer for autism and ADHD diagnoses), in CYPMHS learning disability and autism services, boys wait longer to receive their first contact - a median of 78 days compared to 68 days for girls (see Figure A8). Non-binary children waited notably shorter amounts of time than any other group (a median wait of 39 days), a pattern which is also observed in waiting times for mental health services. Further research is needed to understand this trend, though CCo hypothesises this is possibly related to girls and non-binary children presenting with higher needs at the point of referral.

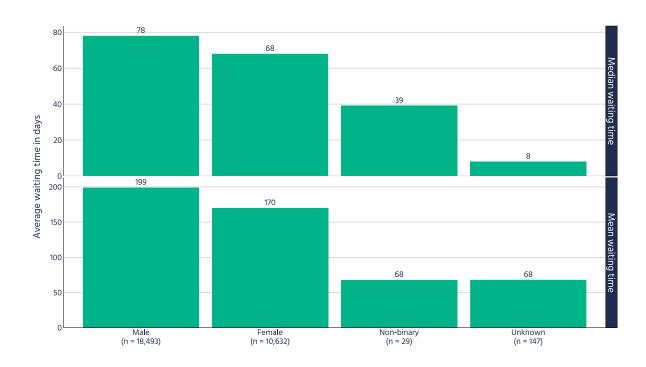
Table A3. Waiting times for children and young people from referral in or before the 2022-23 financial year to their first contact in 2022-23, by gender.

Gender	Number of children referred	% receiving their first contact	Median wait	Mean wait
Male	18,493	63%	78	199
Female	10,632	36%	68	170
Non-binary	29	0.1%	39	68
Unknown	147	0.5%	8	68

Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data



Figure A8: Waiting times in days from referral in or before the 2022-23 financial year to 1st contact with CYPMHS LDA services in 2022-23, by gender.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data

### Differences in waiting times for mental health services by ethnicity

White children and young people make up the largest proportion (56%) of children referred for CYPMHS learning disability and autism services in 2022-23 (16,400 children), followed by children of unknown ethnicity (24%) and Asian children (6.6%). Excluding children of unknown ethnicity, white children comprise 74% of those receiving a contact – roughly the same as the population of white children in England (73%) – see Table A4. Asian children, on the other hand, are under-represented as they comprise only 8.6% of those receiving a contact (despite making up 12% of the child population). Conversely, children of mixed ethnic backgrounds are slightly over-represented (8.3% received a contact compared to 7% of the child population). This mirrors trends observed in community health services (discussed in Chapter 2.7 (all NDD diagnoses), Chapter 2.12 (autism diagnosis) and Chapter 2.16 (ADHD diagnosis)). Children of mixed ethnic backgrounds are slightly over-represented in terms of children receiving a first



contact with CYPMHS learning disability and autism services (8.3% compared to 7% of the child population).

Table A4. Waiting times for children and young people who were referred in or before the 2022-23 financial year received a contact with CYPMHS LDA services in 2022-23, by ethnic group.

Ethnic group	Number of children referred	% who received a contact	Census 2021 population benchmark <sup>2</sup>	Median wait	Mean wait
Asian	1,926	8.6%	12%	92	240
Black	1,243	5.6%	6%	70	194
Mixed	1,859	8.3%	7%	59	211
Other	813	3.6%	3%	36	142
White	16,446	74%	73%	82	188

Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data

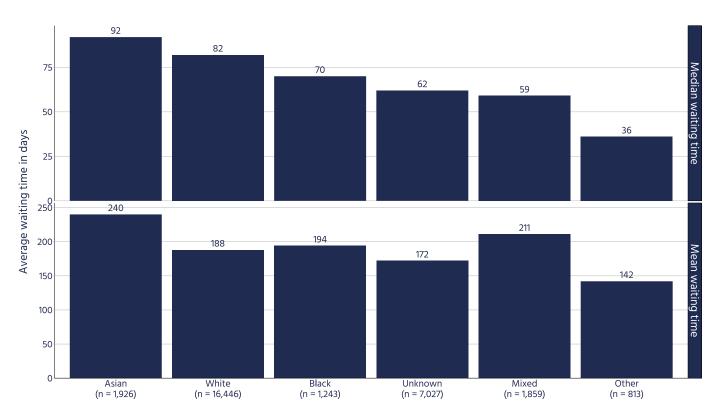
Asian children wait the longest before their first contact (median 92 days or mean 240 days), followed by white children (median 82 days or mean 188 days) – see Figure A9 below. Children with a mixed ethnic background and children of 'other' ethnicities wait the shortest amount of time, with a median wait of 59 days (mean 211 days) and 36 days (mean 142 days) respectively.

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<sup>&</sup>lt;sup>2</sup> ONS. *Children in England*. Census 2021. Link.



Figure A9: Waiting times from referral in or before the 2022-23 financial year to first contact in 2022-23, by ethnic group.



Source: Children's Commissioner's office analysis of previously unpublished Mental Health Services Dataset (MHSDS) data



# List of neurodevelopmental disorder diagnoses included in the CSDS data request

Table A5. Full list of neurodevelopmental disorders included in the data request and their respective SNOMED/ICD names and codes.

Type of neuro- developmental disorder / condition	SNOMED-CT Diagnosis	SNOMED-CT Code	ICD-10 Diagnosis	ICD-10 Diagnosis Code
Intellectual Disor	rders			
	Severe intellectual disability (disorder)	40700009		
	Profound intellectual disability (disorder)	31216003		
	Borderline intellectual disability (disorder)	77287004		



Moderate intellectual disability (disorder)	61152003	
Mild intellectual disability (disorder)	86765009	
Developmental academic disorder (disorder)	1855002	
Primary microcephaly, mild intellectual disability, young-onset diabetes syndrome (disorder)	782755007	
Severe intellectual disability, agenesis of corpus callosum, facial dysmorphism, cerebellar ataxia syndrome (disorder)	1208727002	
Severe intellectual disability, hypotonia, strabismus, coarse face, planovalgus syndrome (disorder)	1197591008	
Severe intellectual disability, progressive postnatal microcephaly, midline stereotypic hand movements syndrome (disorder)	774149004	



Severe intellectual disability and progressive spastic paraplegia (disorder)	778011005		
Severe intellectual disability, progressive spastic diplegia syndrome (disorder)	782723007		
		Mild cognitive disorder	F06.7
		Mild disorder of intellectual development	F70
		Mild disorder of intellectual development	F70.1
		Mild disorder of intellectual development	F70.8
		Mild disorder of intellectual development	F70.9
		Moderate disorder of intellectual development	
		Moderate disorder of intellectual development	F71



	Moderate disorder of intellectual development	F71.0
	Moderate disorder of intellectual development	F71.1
	Moderate disorder of intellectual development	F71.8
	Moderate disorder of intellectual development	F71.9
	Severe disorder of intellectual development	F72
	Severe disorder of intellectual development	F72.0
	Severe disorder of intellectual development	F72.1
	Severe disorder of intellectual development	F72.8
	Severe disorder of intellectual development	F72.9



	Profound disorder of intellectual	F73
	development	
	Profound disorder of intellectual	F73.0
	development	
	Profound disorder of intellectual	F73.1
	development	
	Profound disorder of intellectual	F73.8
	development	
	Profound disorder of intellectual	F73.9
	development	
	Other disorder of intellectual	F78
	development	
	Other disorder of intellectual	F78.0
	development	
	Other disorder of intellectual	F78.1
	development	
	Other disorder of intellectual	F78.8
	development	
	Other disorder of intellectual	F78.9
	development	



			Unspecified disorder of intellectual development	F79
			Unspecified disorder of intellectual development	F79.0
			Unspecified disorder of intellectual development	F79.1
			Unspecified disorder of intellectual development	F79.8
			Unspecified disorder of intellectual development	F79.9
Communication I	Disorders			
	Speech and language developmental delay (disorder)	898051000000104		
	Developmental language disorder (disorder)	280032002		
	Developmental speech disorder (disorder)	1145003		
	Disorder of fluency (disorder)	229621000		



		Childhood autism	F84.0
	Autism spectrum disorder		
<b>Autism Spectrum</b>	n Disorder		
		disorders of scholastic skills	
		Specific developmental	F81
		unspecified	
		speech and language,	
		Developmental disorder of	F809
		of speech and language	
		Other developmental disorders	F808
		Receptive language disorder	F80.2
		Expressive language disorder	F80.1
		disorder	
		Specific speech articulation	F80.0
		disorder	
		Specific speech articulation	F80.0
		language	
		disorders of speech and	
		Specific developmental	F80



			Atypical autism	F84.1
			Asperger's syndrome	F84.5
Attention-Deficit	t/Hyperactivity Disorder			
	ADHD - Attention deficit disorder with	406506008		
	hyperactivity (disorder)			
	Attention deficit hyperactivity	886371000000105		
	disorder, hyperactive impulsive type			
	(disorder)			
	Attention deficit hyperactivity	35253001		
	disorder, predominantly inattentive			
	type (disorder)			
	Child attention deficit disorder	192127007		
	(disorder)			
			Disturbance of activity and	F90.0
			attention	
Specific Learning Disorders				
	Specific learning disability (disorder)	984051000000100		
	Dyslexia	59770006		
	Dysgraphia	88278002		



	Dyscalculia	55640002		
	Learning difficulties (finding)	161129001		
			Specific reading disorder	F81.0
			Specific spelling disorder	F81.1
			Specific disorder of arithmetical skills	F81.2
			Mixed disorder of scholastic skills	F81.3
			Other developmental disorders of scholastic skills	F81.8
			Developmental disorder of scholastic skills, unspecified	F81.9
			Mixed specific developmental disorders	F83
			Pervasive developmental disorders	F84
<b>Motor Disorders</b>				
	Developmental coordination disorder (disorder)	27544004		



	Movement disorder (disorder)	60342002		
			Specific developmental disorder of motor function	F82
			Stereotyped movement disorders	F98.4
Tic Disorders				
	Tic disorder	568005		
			Tic disorders	F95
			Transient tic disorder	F95.0
			Chronic motor or vocal tic disorder	F95.1
			Combined vocal and multiple motor tic disorder [de la Tourette]	F95.2
			Other tic disorders	F95.8
			Tic disorder, unspecified	F95.9
Cerebral palsy				
	Cerebral palsy (disorder)	128188000		
	Ataxic cerebral palsy (disorder)	278512001		



	Dyskinetic cerebral palsy (disorder)	230780007	
	Dystonic cerebral palsy (disorder)	702315006	
	Hemiplegic cerebral palsy (disorder)	43486001	
	Monoplegic cerebral palsy (disorder)	56409008	
	Monoplegic cerebral palsy affecting lower limb (disorder)	230778001	
	Monoplegic cerebral palsy affecting upper limb (disorder)	230777006	
	Spastic cerebral palsy (disorder)	230773005	
Other neurodeve	elopmental conditions/disorders		
	Down syndrome / Complete trisomy 21 syndrome (disorder)	41040004	
	Fragile X syndrome (disorder)	613003	
	22q11.2 deletion syndrome (disorder)	767263007	
	Tuberous sclerosis syndrome (disorder)	7199000	
	Turner syndrome (disorder)	38804009	
	Epilepsy (disorder)	84757009	



Generalized epilepsy (disorder)	19598007	
3-methylglutaconic aciduria type 9 (disorder)	1222672002	
Anterior maxillary protrusion, strabismus, intellectual disability syndrome (disorder)	1222706005	
Congenital insensitivity to pain with severe intellectual disability (disorder)	1237623009	
Congenital suprabulbar paresis (disorder)	1237623009	
Disorder of mitochondrial respiratory chain complexes (disorder)	237986005	
Disorder of the urea cycle metabolism (disorder)	36444000	
Fatty acyl-coenzyme A reductase 1 deficiency (disorder)	1237619001	
Fryns Smeets Thiry syndrome (disorder)	1208344000	
Keppen Lubinsky syndrome (disorder)	1220589007	



Methyl-cytosine phosphate guanine binding protein-2 duplication syndrome (disorder)	702816000		
Neurofibromatosis Type 1 (disorder)	92824003		
Perinatal anoxic-ischemic brain injury	126945001		
Pervasive Developmental Disorders	35919005		
Symptomatic form of fragile X syndrome in female carrier (disorder)	1237344003		
Tuberous sclerosis syndrome (disorder)	7199000		
West Syndrome	28055006		
		Mixed specific developmental disorders	F83
		Pervasive developmental disorders	F84
		Other pervasive developmental disorders	F84.9
		Pervasive developmental disorder, unspecified	F88





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