



Department
of Health &
Social Care

Jonathan Marron CB
Director General, Primary Care &
Prevention
Department of Health and Social Care
39 Victoria Street London
SW1H 0EU

Sir Geoffrey Clifton-Brown MP
Chair of the Public Accounts Committee
House of Commons
London
SW1A 0AA

BY EMAIL –

2nd December 2024

Dear Chair,

Re: Public Accounts Committee oral evidence session: Support for children and young people with special educational needs, 18 November 2024

Thank you for the opportunity to appear before the Committee on Monday 18 November 2024 to discuss support for children and young people with special educational needs and disabilities (SEND).

During the session, I committed to write to the Committee to provide some additional information. There are two annexes attached to this letter which set out:

- Data and measures collected in health and social care related to children and young people with special educational needs and disabilities (SEND) (Annex A)
- Waiting times for children and young people's community mental health services (sometimes also known as child and adolescent mental health services or CAMHS) (Annex B)

I hope that you find this information useful.

Yours sincerely,

Jonathan Marron CB
Director General, Primary Care & Prevention
Department of Health and Social Care



Department of Health & Social Care

ANNEX A: DATA COLLECTED IN HEALTH AND SOCIAL CARE RELATED TO CHILDREN AND YOUNG PEOPLE WITH SPECIAL EDUCATIONAL NEEDS AND DISABILITIES

Data collection	Description of dataset	Example metrics	Data quality / caveats	Link to data
Autism Waiting Time Statistics	<p>These statistics present a group of measures on waiting times for autism spectrum disorder diagnostic pathways, based on the time between a referral for suspected autism and the first care contact associated with that referral.</p> <p>There are also multiple breakdowns based on the progression and outcomes of those referrals.</p>	<p>In September 2024:</p> <ul style="list-style-type: none">• There were 204,876 patients with an open referral for suspected autism (increasing from 163,313 in September 2023).• Of these, 183,200 (89.4%) had a referral that had been open at least 13 weeks (increasing from 138,199 (85%) in September 2023). <p><i>(NB noting the caveat with data for children and young people)</i></p> <ul style="list-style-type: none">• 126,318 (around 62%) of these patients with an open referral are aged 0 to 17 years (an increase from 95,866 in September 2023).• Of these, 113,462 (89.8%) had a referral that had been open at least 13 weeks (an increase from 80,676 (84%) in September 2023).	<p>These are experimental statistics and are published to involve users and stakeholders in their development and remain under constant review.</p> <ul style="list-style-type: none">• The full list of in-scope providers of autism services is unknown and it is likely that some providers of autism services may not be submitting autism data• Autism assessments for children and adolescents happen in two types of NHS service, child and adolescent mental health (CAMH) services and community paediatric services which undertake neurodevelopmental assessment. Activity in CAMH services is reported alongside adult mental healthcare activity in the	<p>Autism Waiting Time Statistics - NHS England Digital</p>



Department
of Health &
Social Care

			<p>Mental Health Services Dataset (MHSDS) and is included in this report. Activity in community paediatric services is reported through the Community Services Dataset (CSDS). Currently autism assessments are not clearly identifiable in CSDS and so cannot be included in this report at present.</p>	
<p>Assuring Transformation</p>	<p>Assuring Transformation (AT) is a commissioner based return for inpatients in a hospital setting who have a learning disability, are autistic or have a learning disability and are autistic.</p> <p>This dataset is used to monitor against the target referred to in the NHS 2024/25 Operational Planning Guidance to reduce the number of people with a</p>	<p>At the end of October 2024, Assuring Transformation data shows that there were 2,050 people with a learning disability and autistic people in inpatient settings. Although this monthly figure is expected to increase (see caveats), this is a 30% net reduction since March 2015 (2,910 inpatients) and a 9% net reduction since November 2023 (2,245 inpatients).</p> <p>Of these inpatients, 215 (10%) were under the age of 18. This is a net reduction of 14% since both March 2017 and November 2023 (250 inpatients aged under 18 at both time points).</p>	<p>NHS England take a snapshot of the data at the end of each month and reports on them on a monthly basis. The data published shows the position as was reported within a “live” system at the end of the reporting month.</p> <p>Commissioners are expected to keep data in the system up to date; however, this is not always possible, and some data are known to be submitted after the period cut-off date. This can result in</p>	<p>Learning Disability Services Statistics - NHS England Digital</p>



Department of Health & Social Care

	learning disability and/or autism cared for in an inpatient unit (total and CYP).		subsequent data releases including upward revisions of data from previous months. All figures are rounded to the nearest 5.	
Mental Health Services Data Set (MHSDS)	The Mental Health Services Data Set (MHSDS) collects data submitted by providers for children, young people and adults who are in contact with mental health services. All activity relating to patients who receive assessments and treatment from Mental Health Services is within scope.	<p>The number of children and young people (CYP) aged 0-17 attending at least one contact (an assessment or treatment) in the rolling 12 months from October 2023 to September 2024 was 798,479.</p> <p>In the period from July - September 2024, for CYP aged 0-17 (including but not limited to those with SEND):</p> <ul style="list-style-type: none">• There were 166,043 referrals supported through NHS funded mental health services with a first contact.• There were 352,682 referrals supported through NHS funded mental health services still waiting for a first contact at the end of the reporting period.	<p>NHS England have been striving to improve the quality of mental health data for a number of years. A key focus has been on increasing the number of mental health service providers submitting to the MHSDS, which now stands at over 370 providers on a monthly basis and an estimated 99%+ of all NHS funded activity (December 2023).</p> <p>To illustrate the quality of the data and the compliance of that data it is presented within a data quality dashboard that reports on the quality of each data item submitted by each provider, allowing for comparisons at a provider, regional and system supplier level.</p>	Mental Health Services Data Set - NHS England Digital



Department of Health & Social Care

<p>Health and Care of People with a Learning Disability</p>	<p>This data provides information about differences in healthcare between people with a learning disability and those without.</p> <p>It contains aggregated data on key health issues for people who are recorded by their GP as having a learning disability, and comparative data about a control group who are not recorded by their GP as having a learning disability.</p>	<p>In 2022/23:</p> <ul style="list-style-type: none">• 0.5% of patients were recorded by their GP as having a learning disability.• The percentage of patients who have a learning disability and:<ul style="list-style-type: none">• an autism diagnosis has had a statistically significant increase each year from 21.4% in 2017-18 to 32.4% in 2022-23.• an ADHD diagnosis has had a statistically significant increase each year from 5.5% in 2017-18 to 8.6% in 2022-23.• a Down syndrome diagnosis has decreased each year from 13.9% in 2017-18 to 11.0% in 2022-23.	<p>These are experimental statistics – this means the indicators are still in the testing phase and have not yet been fully developed. The statistics being used are still being tested for quality and could still be modified.</p> <p>The data may not be representative of all people with a learning disability in England; only 55.1% of patients registered in England in 2022-23 were included in this publication, and these patients are not evenly distributed across the country.</p>	<p>Health and Care of People with Learning Disabilities - NHS England Digital</p>
<p>Community Health Services Waiting Lists</p>	<p>The Community Health Services (CHS) SitRep collects monthly data on waiting lists and waiting times for Children and Young People's (CYP) and Adult's community health services. Providers submit aggregated information for service lines,</p>	<p>In September 2024:</p> <ul style="list-style-type: none">• The total size of the waiting list across all 17 Children and Young People services in scope is 272,718. This is a decrease of 2.1% on August 2024 (278,526).• There is wide variation in the size of waiting lists between CYP services, with the largest waiting lists for community paediatric service (135,074), speech and	<p>This publication contains management data which is collected on a rapid turnaround basis, allowing only minimal validation to be undertaken.</p>	<p>Statistics » Community Health Services Waiting Lists</p>



Department
of Health &
Social Care

	irrespective of the number of ICBs or regions they provide services under.	language therapy (64,604) and audiology (18,362).		
--	--	---	--	--



Department of Health & Social Care

ANNEX B: WAITING TIMES FOR CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

Waiting Times (via NHSE Mental Health Services Monthly Statistics (MHSDS)):

In the period from July – September 2024:

- There were 166,043 referrals for CYP supported through NHS funded mental health services **which received a first contact** (an assessment or treatment) in that period.
- The median waiting time between referral start date and first contact for CYP that **received a first contact** was 19 days.

As of September 2024:

- There were 352,682 referrals for CYP **still waiting for a first contact** with NHS funded mental health services.
- The median waiting time between referral and first contact for CYP **still waiting for a first contact** with mental health services was over 34 weeks, with 10% of CYP referrals which are still waiting for a first contact waiting over 114 weeks.
- Please note a new set of metrics have been introduced into the NHSE MHSDS publication series from September 2024, which utilise a new methodology grouping sets of individual referrals into a referral spell and ending the wait when the patient receives a SNOMED code, giving a more accurate picture of them receiving meaningful help rather than just the first or second contact that a patient has with a service. The statistics presented in this annex do not use this measure as we are currently in the process of developing our understanding of these metrics to ensure consistent and accurate interpretation.

Background Information:

- The supply of mental health services has grown, with a 39% increase in CYP accessing MH services between the year to March 2021 (572,912) and the year to September 2024 (798,479). However, despite this growth, demand for these services continues to exceed supply. The [MHCYP survey](#) (2023) highlighted that the percentage of children aged 8 – 16 years who had a 'probable mental health' disorder increased from 12.5% in 2017 to 20.3% in 2023, and at the end of September 2024, 352,682 CYP were still waiting for a first contact with mental health services.
- The Darzi review found that the rate of MH referrals for CYP has increased by 11.7% a year from around 40,000 a month in 2016 to almost 120,000 a month in 2024. By April 2024, about 1 million people were waiting for contact with mental health services, with 345,000 referrals waiting more than a year for first contact (109,000 of those were CYP).