

**City and Hackney  
Joint Strategic Needs  
Assessment for Children  
and Young People with  
Special Educational  
Needs and Disabilities**

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# City and Hackney Health Needs Assessment for Children and Young People with Special Educational Needs and Disabilities

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## Version control

A minor amendment has been made to a previous version of this report, published on 17<sup>th</sup> October 2024, to remove commentary regarding the reasons for Education Health and Care Plans discontinuing on page 30.

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# Abbreviations and acronyms

AP	Alternative Provision
ASD	Autistic Spectrum Disorder
ASQ-3	Ages and Stages Questionnaire third edition
CFS	Children and Families Services (Social Care)
CIN	Child in Need Plans
CPP	Children on Child Protection Plans
CYP	Children and Young People
EBSNA	Emotionally Based School Non Attendance
EHCP	Education, Health and Care Plan
HES	Hospital Episode Statistics
HI	Hearing Impairment
ICB	Integrated Care Board
ICS	Integrated Care System
JSNA	Joint Strategic Needs Assessments
LA	Local Authority
LAC	Looked-after Children
MLD	Moderate Learning Difficulty
MSI	Multi-Sensory Impairment
NEET	Not in Education, Employment or Training
NEL	North East London
NICE	National Institute for Health and Care Excellence
NSA	SEN support but no specialist assessment of type of need
OHID	Office for Health Improvement and Disparities
OTH	Other difficulty or disability
PD	Physical Disability
PfA	Preparing for Adulthood
PMLD	Profound and Multiple Learning Difficulty
SaLT	Speech and Language Therapy
SDQ	Strengths and Difficulties Questionnaire
SEMH	Social Emotional and Mental Health

SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
SLCN	Speech, Language and Communication Needs
SLD	Severe Learning Difficulty
SPLD	Specific Learning Difficulty
VI	Visual Impairment
YP	Young People

# Executive Summary

## Aim

The primary aim of this health needs assessment is to enhance the understanding of the health and wellbeing needs of children and young people (CYP) with Special Educational Needs and Disabilities (SEND) aged 0-25 years in the City of London and Hackney. This assessment seeks to inform local stakeholders, identify gaps in current provisions, and guide future service planning and commissioning.

## Outline of the report

This report is divided into seven chapters and presents the findings of a health needs assessment for children and young people with SEND in the City of London and Hackney. It provides an overview of national and local policies on CYP with SEND.

The report draws on quantitative data on the local prevalence of CYP with SEND across different age cohorts, type of educational setting, demographics and future projections. It describes the health and wellbeing needs of CYP with SEND carried out through engagement with young people with SEND, their parents and carers and wider stakeholders.

## Methods

The assessment employed a multi-method approach based on the Stevens and Raftery health needs assessment framework, incorporating:

1. **Epidemiological Analysis:** Examining the prevalence and characteristics of SEND at national, regional, and local levels, including age, gender, ethnicity, and deprivation.
2. **Comparative Analysis:** Comparing SEND prevalence and trends over time with North East London, London, and England.
3. **Corporate Analysis:** Gathering stakeholder insights through extensive engagement with 200 residents, including CYP with SEND, their parents and carers, and 17 service providers.

## Key Findings

- **Prevalence and Demographics:**
  - Hackney has a higher SEND prevalence (19%) compared to the North East London average (15%) and national averages (17%).
  - The City of London has the lowest SEND prevalence (12%) among London boroughs.
  - Projections indicate a 31% increase in pupils with an Education, Health and Care Plan (EHCP) in Hackney by 2030, while those receiving SEN support are expected to decrease by 30%.
  - There are inequalities in SEND prevalence across different groups. The SEND prevalence was higher amongst boys; certain ethnic groups like White and Black



Caribbean, Black Caribbean, Black African or other, Traveller of Irish heritage and White British and Irish; English speakers; CYP entitled to free school meals and an over representation of CYP with SEND in the youth justice system.

- The primary educational need of CYP with SEND varied across phases of education and by SEN provision. The primary needs of those with an EHCP was mainly Autism Spectrum Disorder. Among those with SEN support, the main primary needs were speech, language and communication in the early years, whereas emotional and mental health needs were the most common primary needs among those with SEN support in secondary school and the YP in the youth justice system.

- **Health and Wellbeing Needs:**

- Data on health needs is limited, particularly for those with SEN support.
- Medical needs are under-reported on the EHCP records. Where these were recorded, the most common medical needs were epilepsy, allergies, eczema, Down's syndrome, asthma, continence, constipation and heart related conditions.
- Key health service accessed by CYP with SEND, where data was available was speech and language therapy. Although the total number of referrals into SaLT for children and young people living in the City of London and Hackney has remained relatively stable since 2018, there was a noticeable increase in the proportion of those who were referred at a younger age between 2018 and 2023.
- Poor emotional health is more common amongst Looked After Children with SEND compared to those without SEND.

- **Stakeholder Insights:**

- **Children and Young People with SEND:** Identified areas for improvement in health and wellbeing services, including better communication and integration of services.
- **Parents and Carers:** Emphasised the need for improved support in schools, better health services, and addressing social determinants of health.
- **Service Providers and Professionals:** Suggested improvements in referral systems, timelines, and addressing inequalities.

## **Recommendations**

1. **Communication, Information, and Advice:** Enhance communication strategies to ensure clear, accessible information for families and professionals.
2. **Diagnosis and Early Intervention:** Improve early identification and intervention processes to ensure timely support for CYP with SEND.
3. **Access to Services:** Increase accessibility and availability of health and wellbeing services for CYP with SEND.
4. **Addressing Inequalities:** Implement targeted strategies to address health and social inequalities affecting CYP with SEND.
5. **Data and Records:** Improve data collection and sharing practices to ensure comprehensive and accurate records of CYP with SEND.
6. **Social Determinants of Health:** Address broader social determinants impacting the health and wellbeing of CYP with SEND, including poverty and housing.

# Chapter 1: Background and Introduction

## Background and introduction

Joint Strategic Needs Assessments (JSNAs) are carried out by local authorities, in partnership with stakeholders and partners from across Integrated Care Systems (ICS), to assess the current and future health and wellbeing needs of the local population. The process supports the development of local policies, strategies, and health interventions, and informs service planning and commissioning.

A new Special Educational Needs and Disabilities (SEND) JSNA will provide an up to date understanding of the needs of Children and Young People (CYP) with SEND in the City of London and Hackney, identify gaps in the local offer, enable the development of more inclusive SEND provision and help plan for future SEND needs through local commissioning plans.

## Aims and objectives

This health needs assessment aims to improve local stakeholder's knowledge and understanding of the health and wellbeing needs of CYP aged between 0 and 25 years, with SEND living in the City of London and Hackney.

The objectives of this needs assessment are as follows:

- 1) To describe the population of children and young people with SEND.
- 2) To identify the health and wellbeing needs of children and young people with SEND.
- 3) To identify current gaps in local knowledge and understanding of the needs of children and young people with SEND.
- 4) To provide a high level overview of the relevant national and local policy context on children and young people with SEND.
- 5) To develop recommendations based on the findings of this needs assessment, to inform future services and commissioning plans for children and young people with SEND.

## Methodology

The following three methods were used, based on the Stevens and Raftery health needs assessment approach (1) :

1. **Epidemiological** (assessing the prevalence and health needs by different characteristics): This includes the prevalence of SEND at national, regional and local authority level. It also includes who is affected by age, gender, ethnicity, deprivation,

and other available characteristics in the SEND cohort. We also gathered data on health conditions that affect CYP with SEND, however limited data were available for inclusion in this report. The key sources of data used in this report were from the Department for Education; service providers including Education, Health and Children's Social Care; OHID; and NHS Digital.

2. **Comparative** (comparison with other areas and over time): This needs assessment includes comparisons of prevalence of SEND amongst different age groups, trends and projections over time as well as with North East London, London and England.
3. **Corporate** (incorporating stakeholder views and expertise): This involves eliciting views of stakeholders including CYP with SEND, parent/carers and professionals. City of London and Hackney's Public Health Team carried out extensive stakeholder engagement between December 2023 to March 2024, with a total of 200 residents including young people with SEND, their parents and carers and 17 service providers.

In this report, numerical figures presented in the text are rounded to the nearest whole number, while figures represented in charts are rounded to one decimal place for clarity and ease of interpretation.

## Governance

This work was overseen by a CYP SEND Needs Assessment Steering Group that was established by the City of London and Hackney Public Health Team. The group included representation from SEND, ICS, Primary care, Children's Social Care and Public Health. Regular updates on progress for this report were also taken to the Children & Education Senior Leadership Team and SEND Partnership Boards for the City of London and Hackney.

## Defining SEND cohorts included in this report

This report refers to two key cohorts of CYP with SEND. The definitions and types of SEND are included in Chapter 2 of this report:

- CYP with SEND (both SEN support and EHCP) who are City or Hackney residents and registered in a local school. This cohort also includes CYP with SEND (both SEN support and EHCP) who are registered in a school in the City of London or Hackney, but live outside these areas (only school census data was available for this cohort, details of their EHCP were not available).
- CYP with SEND who have an EHCP maintained by City or Hackney, but are registered in a school outside these areas or are homeschooled / out of school register.

It does not cover CYP with SEN support who are City of London or Hackney residents and registered in a school outside these areas, homeschooled or out of school.

# Chapter 2: SEND Definitions and Risk factors for SEND

## Definitions

The Special Educational Needs and Disability Code of Practice (2015) defines SEN as follows:

“A child or young person has **SEN** if they have a learning difficulty which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

has a significantly greater difficulty in learning than the majority of others of the same age, has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream-post 16 institutions.”

For children aged two or more, special educational provision is education or training provision that is additional to, or different from, that generally is made for other children of the same age. For a child under the age of two, special educational provision means education provision of any kind. A child under compulsory school age has special educational needs if he or she is likely to fall within the definition shown above when they reach compulsory school age, or would do so if special educational provision were not made available for them.

The SEND Code of Practice further defines CYP with a **disability** as follows:

“Many children and young people who have SEN may have a disability under the Equality Act 2010 – that is ‘...a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities’. This definition includes sensory impairments such as those affecting sight or hearing, and long-term health conditions such as asthma, diabetes, epilepsy, and cancer. Children and young people with such conditions do not necessarily have SEN, but there is a significant overlap between disabled children and young people and those with SEN. Where a disabled child or young person requires special educational provision they will also be covered by the SEN definition. “

**Special Educational Needs and Disabilities** can affect a **child or young person’s** ability to learn in many different ways. There are two levels of support available to children or young people with **Special Educational Needs and Disabilities**:

- **Special Educational Needs Support (SEN Support):** This additional support is offered to the child or young person at their school or college. The aim is to help the child or young person achieve outcomes that are jointly developed between the

school and parents/carers. Some examples of SEN support are: a special learning programme; extra help from a teacher; making or adapting materials and equipment; support for the child/young person in a small group.

- **Education Health and Care Plan (EHCP):** An education, health and care plan is for **children and young people** up to the age of 25 years who need more support than is available through SEN support. It includes an assessment of the child or young person’s educational, health and social needs and sets out extra support required to meet them. (2)

**Table 1: SEND categories used to describe SEND in the School Census**

Broad area of need	Category of SEN
Cognition and Learning	<ul style="list-style-type: none"> <li>● Specific Learning Difficulty (SPLD)</li> <li>● Moderate Learning Difficulty (MLD)</li> <li>● Severe Learning Difficulty (SLD)</li> <li>● Profound and Multiple Learning Difficulty (PMLD)</li> </ul>
Communication and Interaction	<ul style="list-style-type: none"> <li>● Speech, Language and Communication Needs (SLCN)</li> <li>● Autistic Spectrum Disorder (ASD)</li> </ul>
Social, Emotional and Mental Health Difficulties	<ul style="list-style-type: none"> <li>● Social Emotional and Mental Health (SEMH)</li> </ul>
Sensory and/or Physical Needs	<ul style="list-style-type: none"> <li>● Hearing Impairment (HI)</li> <li>● Visual Impairment(VI)</li> <li>● Multi-Sensory Impairment (MSI)</li> <li>● Physical Disability (PD)</li> </ul>
Other	<ul style="list-style-type: none"> <li>● Other difficulty or disability (OTH)</li> <li>● SEN support but no specialist assessment of type of need (NSA)</li> </ul>

Source: Department for Education, Special educational needs in England type of need, 2023.

## Risk Factors for SEND

The following section outlines the key risk factors that affect a **child or young person with a Special Educational Need or Disability**.

**Table 2: Risk Factors for SEND**

Risk Factors for SEND	
1. Prenatal, perinatal and early childhood	<ul style="list-style-type: none"> <li>● National Institute for Health and Care Excellence (NICE) lists a range of conditions that are risk factors for people with learning disabilities during the prenatal, perinatal and early childhood period. (3).</li> <li>● <b>Gestational Age:</b> A study aimed to examine the risk of SEN across the full gestation period. It showed that gestational age at delivery is strongly associated with a</li> </ul>

	<p>child's risk of having a SEN. The study demonstrated a strong trend of decreasing risk of SEN with advancing gestational age at birth. There was a very strong association with extreme preterm delivery (24-27 weeks). The risk steadily declined with increasing gestational age up to 40-41 weeks, but then increased among those who delivered at 42 weeks. (4)</p> <ul style="list-style-type: none"> <li>● <b>Low birthweight:</b> Low birth weight has been cited as a risk factor for developmental delays in children in a study assessing the cognition, school performance and behaviour of children at the age of 8 years. The study showed that the majority of children with very low birth weight were developing normally and their reading and performing in most academic and social areas was as good as children with normal birth weight. However, there were certain areas where children with very low birth weight were found to be significantly worse off. This included tests of cognition, including tests of intelligence, visual memory, motor skills and initiative as compared to children with normal birth weight. Higher proportion of parents with children with very low birth weight reported that their children were not coping well at school, compared to those with normal birth weight. (5)</li> </ul>
<p><b>2. Personal and Environmental factors</b></p>	<ul style="list-style-type: none"> <li>● NICE also includes personal and environmental factors that put a person with a learning disability more at risk of challenging behaviour such as <b>aggression, self-harm, social withdrawal, disruptive or destructive behaviour.</b> (6)</li> </ul>
<p><b>3. Socio-economic factors</b></p>	<ul style="list-style-type: none"> <li>● <b>Poverty</b> is both a cause and effect of SEND. Children with SEND are more likely to be poor, while children living in poverty are more likely to develop SEND. They are also less likely to experience their full educational potential and leave education with outcomes that increase the chances of living in poverty in their adult life. The Joseph Rowntree Foundation (JRF) report recommends that policy makers and early years leaders prioritise SEND, training of staff in early years settings and schools for early identification of SEND, and targeted funding for pupils with SEND who are at risk of being excluded. (7)</li> </ul>

# Chapter 3: Policy Context

## National policies and guidance included in this report are:

Table 3. National policies and guidance related to SEND

<p><b>Children and Families Act (2014)</b></p>	<p>The Children and Families Act (2014) includes in depth guidance and requirements for local authorities in relation to children and young people with special educational needs or disabilities. Local authorities have a responsibility to integrate education, training, healthcare, and social care where this would promote the wellbeing of children and young people with SEND. It extended the support for CYP with SEND from 0-25 years and replaced SEN statements with EHCPs.</p>
<p><b>Care Act (2014)</b></p>	<p>The Care Act (2014) includes detailed requirements for local authorities to provide care and support for children transitioning to adult care.</p>
<p><b>NICE guidance (2016)</b></p>	<p>NICE guidance (2016): provides guidance on the transition from children’s to adult services for young people using health or social care services.</p>
<p><b>The SEND Code of Practice (2015)</b></p>	<p>The SEND Code of Practice (2015) provides statutory guidance for organisations that work with and support CYP with SEND. It sets out the broad areas of need including: cognition and learning; communication and interaction; social, emotional and mental health difficulties, and sensory and physical needs.</p>
<p><b>Government SEND review (2023)</b></p>	<p>Government SEND review carried out in 2023 focuses on: a) fulfilling children’s potential: b) build parents’ trust and c) provide financial sustainability.</p>
<p><b>The Children’s Commissioner of England report (2023)</b></p>	<p>The Children’s Commissioner of England report (2023) recommends: a) To be understood, seen and heard with improved early identification, better data, access to advocacy being key areas of improvement: b) Good education and support in schools; c) Accessible activities; d) High quality care; e) Freedom from harassment and discrimination; f) Smooth transition and preparing for adulthood; and g) A whole family approach.</p>

## The local policies included in this report includes:

Table 4. Local policies related to SEND, City and Hackney

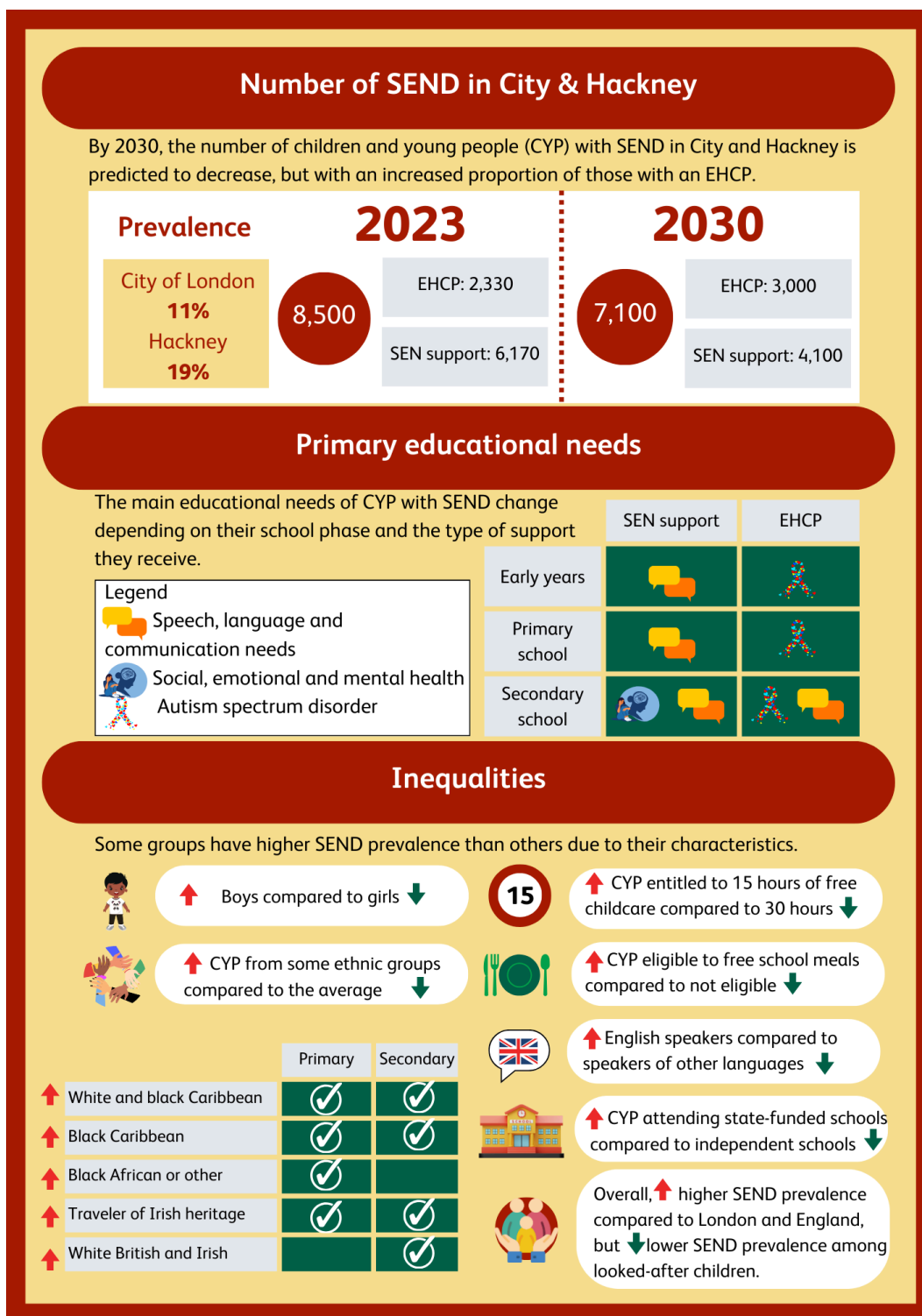
<b>Hackney Young Futures Commission report</b>	<p>The Hackney Young Futures Commission report consulted with young people in the borough. Key themes that emerged were focused on a bright, secure, active, inclusive, safe and healthy future.</p>
<b>SEND Strategy, City of London 2020-24</b>	<p>SEND Strategy, City of London 2020-24 aims to provide an inclusive and safe environment where children and young people can learn, achieve and participate with other children and young people. The City of London SEND strategy is being refreshed and engagement is being carried out at the time of writing this report. The new SEND strategy is planned to be in place for 2025-2029.</p>
<b>Hackney’s SEND Strategy 2022-25</b>	<p>Hackney’s SEND Strategy 2022-25 envisions providing an excellent, inclusive and equitable local experience for all Hackney CYP with SEND.</p>
<b>Hackney’s Preparing for Adulthood strategy (2024-27)</b>	<p>Hackney’s Preparing for Adulthood strategy (2024-27) is currently unpublished, and will focus on four key priorities: active listening of views of YP and their families; system wide partnership; provide clear and accessible information; identify opportunities for joint commissioning.</p>

Detailed national and local policies for CYP with SEND are included in **Appendix 1** of this report.



# Chapter 4: Local picture

## Chapter Summary

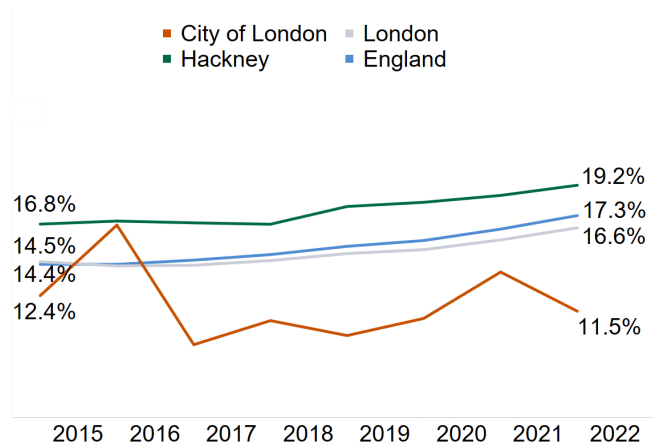


Sources: Department for Education, Special educational needs in England, 2023. SEN2 Return to DfE - Normalised to total school population within LA, 2021/22. Education provision: children under 5 years of age.

## Current SEND prevalence

In the academic year 2022/23, **Hackney** had the seventh highest SEND prevalence out of 32 London boroughs plus the City Corporation, among pupils registered at both state maintained and independent schools. This equates to 19% of **children and young people** registered at schools in Hackney having SEND. This is higher than the North East London (NEL) average (15%), and the averages for London and England (both 17%). Locally, regionally and nationally, SEND prevalence has been rising since 2015/16 (Figure 1). (8)

**Figure 1: Trend in the prevalence of children and young people with SEND by area, 2015/16 to 2022/23**



Source: Department for Education, Special educational needs in England, SEN phase type by SEN provision, type of need and school type, 2023.

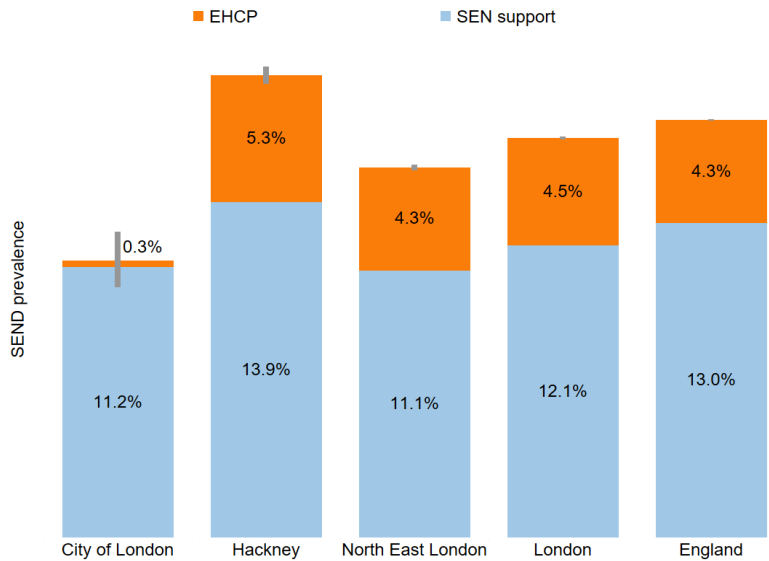
Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools, alternative provision schools and independent schools.

The percentage of pupils with SEND in **Hackney** is higher than comparators. This is the case for both CYP who receive SEN support and those with an EHCP (Figure 2). The proportion of pupils with SEND shown in Figure 2 relates to pupils who attend school in the City of London or Hackney independently of where they live.

Table 5 summarises what we know about the number of pupils with SEND in Hackney and the City of London as well as the number of CYP residents with SEND. The number of resident CYP with SEND for Hackney is not available because the number of CYP receiving SEN support attending school outside the borough is currently unknown. (9)

The City of London has recently completed a census of their resident CYP receiving SEN support. This involved contacting over 80 schools to confirm whether City residents with SEN support were attending their settings. By September 2024, the City of London identified 53 pupils with SEN support out of 332 City residents attending schools in or out of the Corporation. It is worth noting that the total number of pupils with SEN identified is lower than the number of City residents aged 5 to 16 identified by Census 2021 (402).

**Figure 2. Proportion of pupils with Special Education Needs and Disabilities by provision and area, City and Hackney and comparator areas, 2022/23**



Source: Department for Education, Special educational needs in England, SEN phase type by SEN provision, type of need and school type, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools, alternative provision schools and independent schools.

EHCP: education, health and care plans

SEN: special education needs, includes disabilities

**Table 5. Children and young people with special education needs and disabilities included in this report, 2023**

	Hackney	City of London
<b>Pupils: number of CYP with SEND attending schools locally</b>	8,500	67
• CYP with an EHCP	2,230	8
• CYP with SEN support	6,170	59
<b>Residents: number of CYP with SEND living in the local area</b>	unknown	77
• CYP with an EHCP	3,520	24
• CYP with SEN support	unknown	53

Source: Department for Education, Special educational needs in England, SEN phase type by SEN provision, type of need and school type, 2023; London Borough of Hackney. EHCP Annex A (not publicly available); City of London Corporation. EHCP caseload anonymised (not publicly available), Oct 2024.

In **Hackney** schools, there are 2,330 pupils with an EHCP (Table 5), which accounts for 5% of the total number of pupils. Additionally, 6,170 pupils receive SEN support (Table 5), which equates to 14% of the total pupils. Altogether, this results in a total of 8,500 pupils with SEND, constituting 19% of the total pupil population in the academic year 2022/23. (8)

The **City of London** has the lowest proportion of CYP with SEND attending school (12%) of the 32 London boroughs plus the City Corporation. (8) There were eight pupils (accounting

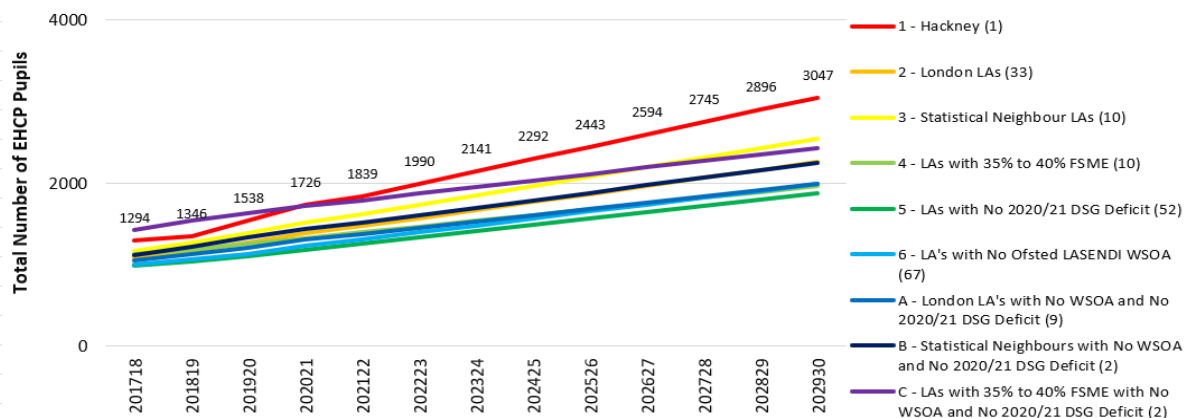
for 0.3% of the school population) and 24 CYP residents with an EHCP<sup>1</sup>. Additionally, 59 pupils (11.2% of the City of London’s total pupils in 2022/23) and 53 residents were identified as receiving SEN support<sup>1</sup> (Table 5).

The City of London is unique because of the size of the population and there only being one primary school in the area. Most of the children who attend this school live outside of the City of London. There is no state maintained secondary school in the City of London and all secondary aged pupils attending state maintained schools access provision outside of the City of London.

## SEND projections

Projections indicate that by 2030, the number of pupils with an EHCP going to school in Hackney is expected to increase by 31% from 2,330 to 3,047 (Figure 3). By contrast, the number of CYP receiving SEN support is expected to decrease by 30%, from 6,170 to 4,341 (Figure 4). Overall, there is projected to be a 14% reduction in SEND prevalence in 2030 from 2023. This includes pupils in independent schools. (10) The reasons for the reduced numbers are unknown.

**Figure 3. Number of children and young people with Education, Health and Care Plan by time period, Hackney and comparators, 2017/18-2029/30**

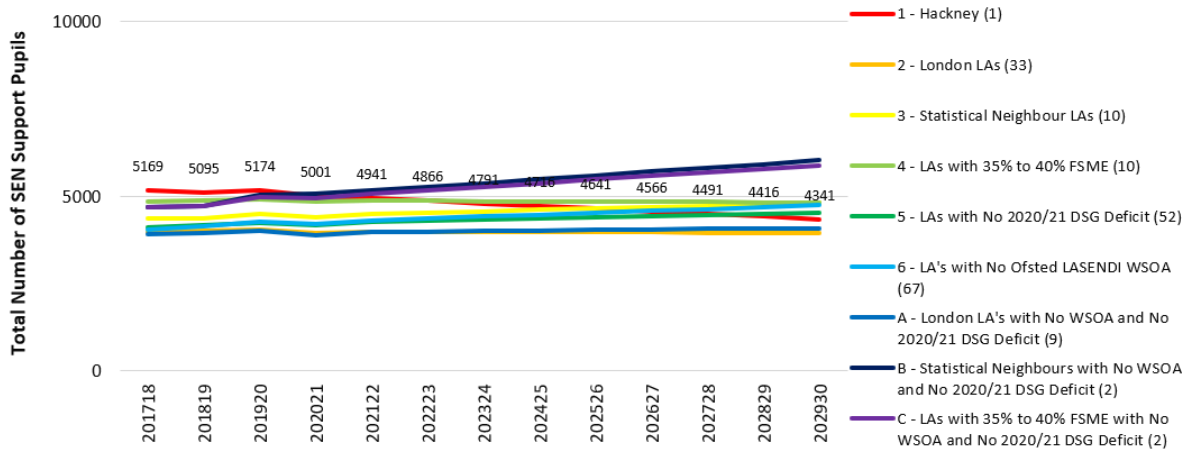


Source: SEN2 Return to DfE - Normalised to total school population within LA, 2021/22

Note: This image was copied from the Hackney Commissioning Strategy, June 2023.

<sup>1</sup> Note that there is likely to be an element of double counting between the number of pupils and the number of residents with SEND.

**Figure 4. Number of children and young people with special education needs by time period Hackney and comparators, 2017/18-2029/30**



Source: SEN2 Return to DfE - Normalised to total school population within LA, 2021/22

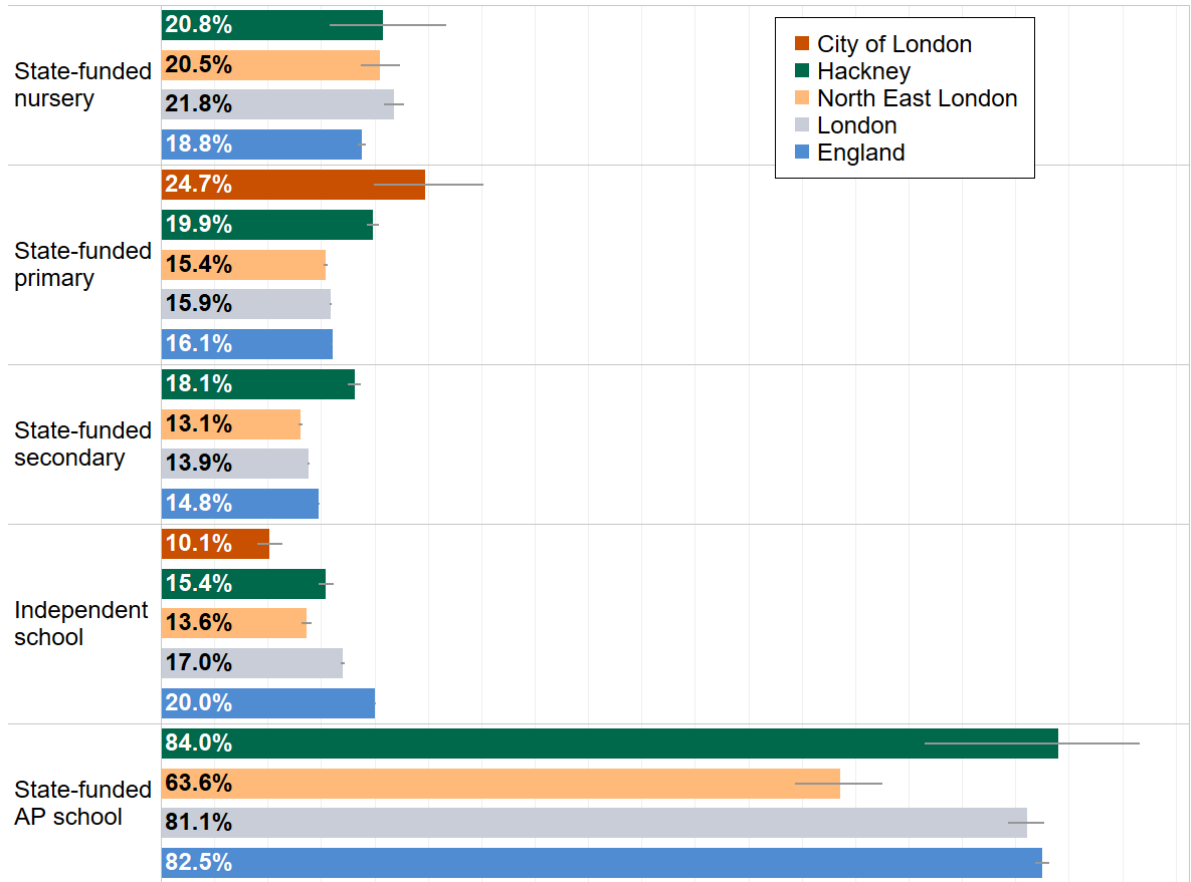
Note: This image was copied from the Hackney Commissioning Strategy, June 2023.

Projection data was not available for the City of London. However, despite the **City of London's** small population, there was a 77% increase in CYP with an **EHCP** between September 2017 and September 2023, from 13 to 23 CYP. (11)

## SEND prevalence by school type

The prevalence of SEND among CYP varies by school type. Independent schools in both the City and Hackney have a statistically significant lower prevalence of SEND among CYP compared to other types of schools. Notably, the difference in the City is even more pronounced than in Hackney (Figure 5). When we exclude independent schools, Hackney moves from having the seventh to the third highest proportion of SEND in London, while the City moves from the lowest to the highest position. (8)

**Figure 5. Prevalence of pupils with special education needs provision, by type of school and area, City and Hackney and comparator areas, 2022/23**



Source: Department for Education, Special educational needs in England, SEN phase type by SEN provision, type of need and school type, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools, alternative provision schools and independent schools.

The City of London has a state-funded nursery at the only primary school in the area and has SEND children attending the class despite the data not being available in the public data. The data has not been added to the chart due to the number of CYP with SEND being under eight.

SEND: special education needs and disabilities, include special education needs support and education, health and care plans.

AP: alternative provision

State-maintained special schools are publicly funded educational institutions, specifically dedicated to providing tailored education and support for CYP with SEND. Hackney has three state-maintained special schools: Stormont House School, the Garden School (which has two sites; the Garden and the Pavilion), and Ickburgh School. There are also two independent special schools (Side By Side School, which is an Orthodox Jewish school, and Leaways School). As expected, all children in special schools in Hackney have SEND. There are no special schools within the City of London.

Alternative provision (AP) schools provide education for CYP of compulsory school age who do not attend mainstream or special schools and who would not otherwise receive suitable education. These include permanently excluded CYP, and other CYP who

would not receive suitable education without such arrangements being made, because of illness or other reasons. (12) In Hackney, there are two state-funded AP schools: The Boxing Academy AP Free School and New Regent's College.

In the academic year 2022/23, 42 pupils with SEND (including SEN support and EHCP) attended the AP schools in Hackney. This represents 84% of the 50 pupils enrolled in these schools; a notably high percentage compared to other types of schools in Hackney. The higher percentage of SEND among CYP in AP schools is also observed in NEL, London and England (Figure 10). The City of London does not have any state-funded AP schools. (8)

## **SEND throughout phases**

The following sections only include data relevant to CYP attending state-maintained schools in Hackney and the City of London. No data is available for CYP attending independent schools.

Historically, the prevalence of SEND in state-funded nurseries was lower than in primary and secondary school. For example, in 2019/20, 11% of pupils in state-funded nurseries had SEND and this increased to 18% among primary and secondary school pupils in Hackney. In 2022/23, this was not the case as there was a significant increase in the prevalence of SEND among children in state-funded nurseries, which reached 21%, likely due to their development being affected by the lockdowns. (13)

Early identification is important to ensure the right support is provided for children with SEND. This can happen at different stages outlined below, during the antenatal period, birth, early years and school age.

### **Maternity**

Midwifery plays an important role in antenatal and newborn screenings. Midwives perform antenatal checks to help identify genetic conditions, developmental delays and risk factors that may affect the child's development. After babies are born, newborns are screened for several genetic disorders and metabolic conditions that may not be apparent at birth. This is done via a blood test obtained from a heel prick. Newborn screening also includes assessment for hearing loss and vision impairment. (14)

In 2023, 58% of women who delivered at Homerton hospital, which is the main maternity hospital for Hackney residents, had their antenatal booking appointments within 10-weeks of birth, as recommended. This is statistically similar to London (59%) and England (61%). (15) The number of deliveries from City of London residents by NHS trust is too small to give an accurate reflection of the City of London's resident population giving birth.

## Health Visiting

The Healthy Child Programme, delivered by health visitors, offers five mandated health visitor contacts, including one antenatal check and four baby checks, within 14 days, at 6-8 weeks, at 12-months, and at 2-2.5 years. Additional support through the intensive health visiting contacts for vulnerable families in the City of London and Hackney is also provided. (16)

At the two-year check, children receive an 'Ages and Stages Questionnaire third edition' (ASQ-3) assessment for child development. Children with suspected development delays then receive another assessment to gauge further development needs and determine whether onward referrals to specialist services are needed.

### Box 1: Ages and Stages Questionnaire

The ASQ-3, or Ages and Stages Questionnaire, third edition, is a developmental screening tool used by healthcare professionals to assess children's development in various domains such as communication, fine motor skills, gross motor skills, problem-solving, and personal-social skills. In England, it is typically administered to children at their 2 to 2½-year review. (17)

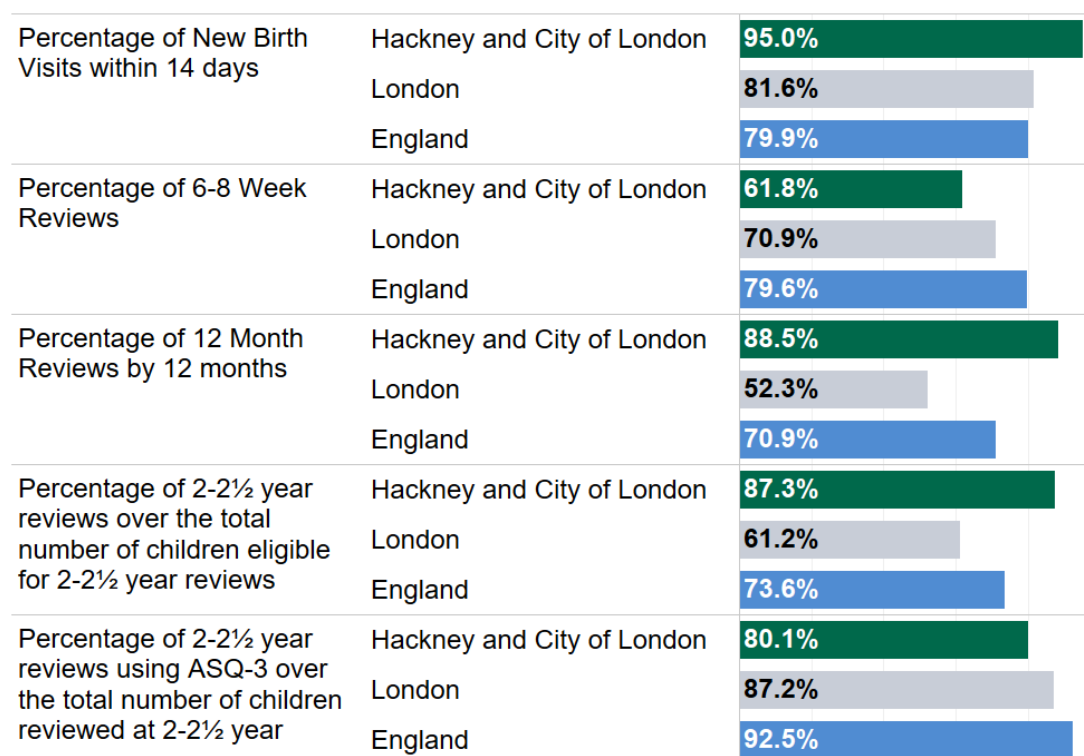
A review without this screening tool could still potentially detect developmental delays. This is paramount for early intervention and support services that are pivotal for the child's long-term development.

However, only a standard measure allows to track changes in population health from year to year, assess the effectiveness and impact of services for 0 to 2-year-olds, and support planning.

In 2022/23, the proportion of babies and children receiving the health visitor checks in the City of London and Hackney combined, was higher than the London and England averages for all reviews except the 6-8 week review and the reviews using ASQ-3 (Figure 6). This has remained consistent throughout the years. (18)



**Figure 6. Percentage of children reviewed at health visiting checks, City of London and Hackney, 2022/23**



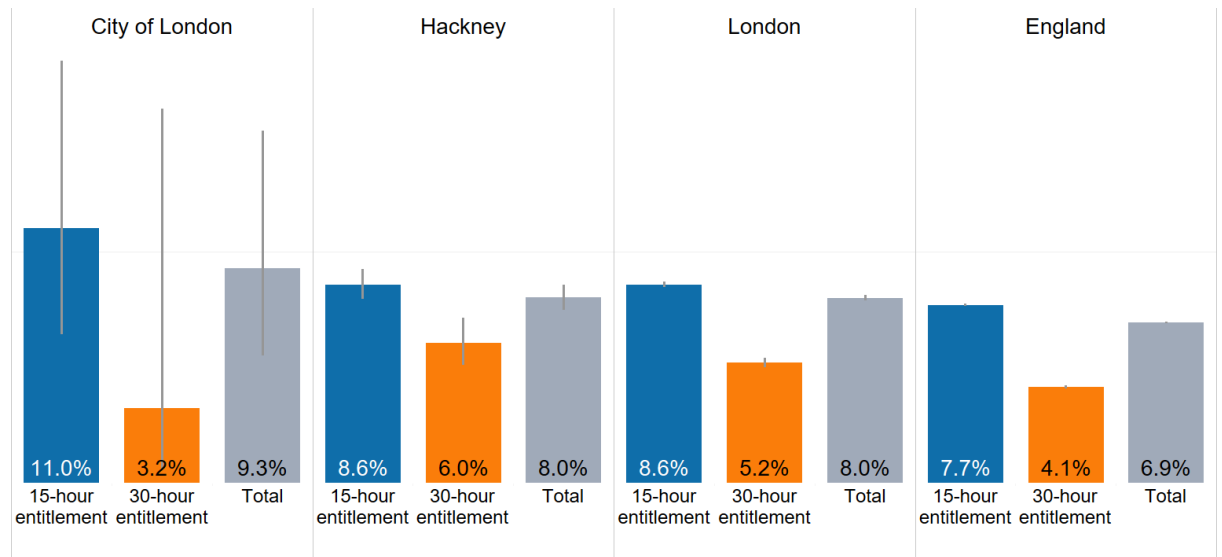
Source: OHID, Health visitor service delivery metrics: annual data April 2022 to March 2023

### Early years educational settings

There is funding to assist children with emerging SEND in early years education. This is called the SEN Inclusion Fund. All local authorities must have this funding for children with emerging SEND who are aged three and four years old. This has been extended to younger children from 9 months under the expansion of the entitlement for working families. All early years providers, including private, voluntary, independent settings, childminders, and nursery classes, can obtain this funding if they offer free childcare places following the government criteria. (19) Beyond what was required, the City of London and Hackney has extended this support to children aged two years receiving free childcare places, even before the release of new guidance to include two year olds in 2024.

In 2022/23, the proportion of children with SEND (including both EHCP and SEN support) among those aged between two and four years and registered in early years provision in the City of London and Hackney was similar to London and higher than England. Those entitled to 15-hours of free childcare a week had a higher SEND prevalence than children entitled to 30-hours in all areas (Figure 7). Although the definite reasons for this are unknown, the possible explanation might be that families that are entitled to 15 hours work fewer hours due to their caring responsibilities of CYP with SEND, compared to families with 30 hours entitlement. Another explanation could be some settings might not be offering more than 15 hours to CYP with SEND.

**Figure 7. Prevalence of pupils with special education needs provision, by type of free childcare entitlement, City and Hackney and comparator areas, 2022/23**



Source: Department for Education. Education provision: children under 5 years of age. Children registered by ethnicity and SEN provision, 2023.

Note: The vertical lines represent confidence intervals, which are a way to estimate the range of values that we can be reasonably confident contain the true value we are trying to estimate.

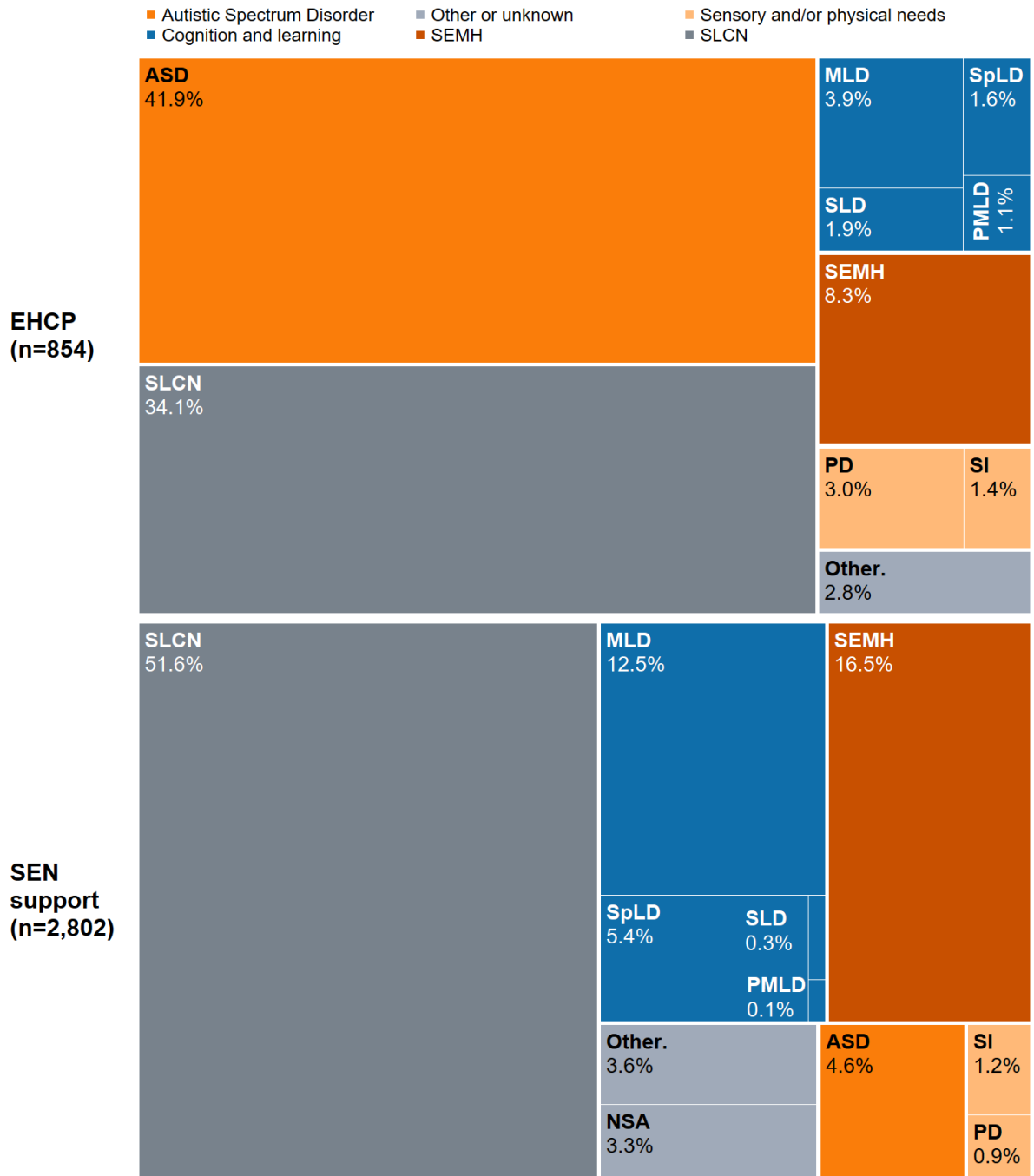
Half of all children with an EHCP in Hackney early years were autistic. Among children with SEN support attending early years, speech, language and communication needs were the most common need (71%). (8)

In the **City of London**, 13 out of the 140 children registered in early years provision in 2022/23 had SEND. (20)

### Primary school

In **Hackney primary schools**, the primary educational need of children with EHCP is autism support. For CYP with SEN support, this is speech, language and communication needs. (Figure 8) This aligns with the national trend. (21)

**Figure 8. Prevalence of primary school pupils with special education needs by primary need and provision, Hackney, 2022/23**



Source: Department for Education, Special educational needs in England, FSM, Ethnicity and Language, by type of SEN provision and type of need, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools and state-funded alternative provision schools. Does not include independent schools.

SEN: special education needs, includes disabilities

EHCP: education, health and care plans

SpLD: specific learning difficulties; MLD: moderate learning difficulty; SLD: severe learning difficulty; PMLD: profound and multiple learning difficulty; SLCN: speech, language and communication needs; SEMh: social, emotional and mental health; ASD: autistic spectrum disorder; SI: sensory impairment (includes visual, hearing and multisensory impairment); PD: physical disability; Other: other disability/difficulty; NSA: receive 'SEN support' but there was no specialist assessment of type of need.

In the one **City of London primary school**, although the numbers are too small to be presented, similar to what has already been observed in Hackney and nationally, autism support is more commonly required among children with an EHCP, while speech, language and communication needs are more common among children with SEN support. (8)

### **Secondary school**

The **City of London** doesn't have any state-funded secondary schools.

In **Hackney's state-funded secondary schools**, the primary educational needs of CYP with an EHCP are concentrated on autism support and speech, language and communication needs, while the needs of those with SEN support are focused on social, emotional and mental health and speech, language and communication needs. (Figure 9) (8)

### **Preparing for adulthood**

The SEND Code of Practice (2015) sets out a wide-ranging set of mandated responsibilities for local area partnerships around supporting and preparing CYP with SEND from the earliest years to transition from childhood into adulthood. It is referred to as 'preparing for adulthood'. (22) Being supported towards greater independence, and employability can be life-transforming for CYP with SEND. This support should start in the early years settings and schools, with a greater focus from Year 9, and should centre around the child or young person's aspirations, interests, and needs.

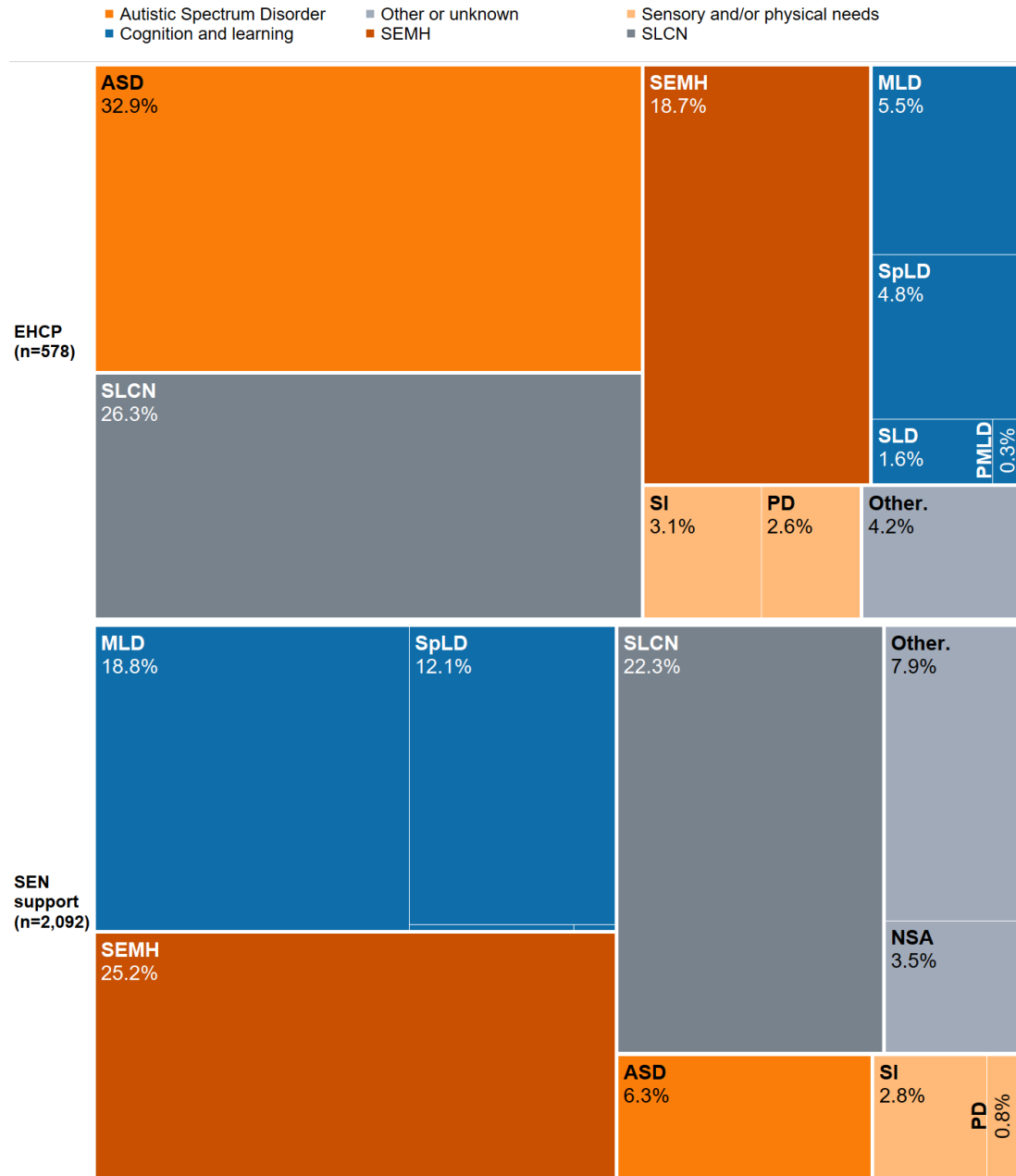
Analysis of YP aged 16+ with an EHCP maintained by the **City of London** is not possible due to the low number of individuals. (11) There are no public funded sixth form colleges or further education colleges in the CoL, so YP attend sixth form and further education provisions in other local authorities.

The CoL's Transitions forum, which includes partners from education, health, and social care, meet quarterly to fulfil its duties under the Care Act 2014 in ensuring a smooth transition into adult social care and health services. This process starts from Year 9. The CoL is also building support structures to encourage YP to engage with apprenticeships, traineeships, and supported internships within the CoL. For example, the SEND Employment Forum aims to encourage local businesses to provide opportunities for YP with SEND. However, due to the current cohort, no YP with an EHCP is currently accessing this support.

In October 2023, around 1,220 YP aged 16+ had an EHCP maintained by **Hackney**. (9) However, for over half of these YP, their educational establishment was not recorded. Out of the total with an educational establishment recorded, around one in five attended special schools, another one in five, colleges, and another one in five,

academies. The remaining attended independent schools, free schools, local authority-maintained schools or other arrangements.

**Figure 9. Prevalence of secondary school pupils with special education needs by primary need and provision, Hackney, 2022/23**



Source: Department for Education, Special educational needs in England, FSM, Ethnicity and Language, by type of SEN provision and type of need, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools and state-funded alternative provision schools. Does not include independent schools.

SEN: special education needs, includes disabilities

EHCP: education, health and care plans

SpLD: specific learning difficulties; MSPMLD: moderate, severe or profound and multiple learning difficulty; SLCN: speech, language and communication needs; SEMHS: social, emotional and mental health; ASD: autistic spectrum disorder; SI: sensory impairment (includes visual, hearing and multisensory impairment); PD: physical disability; Other: other disability/difficulty; NSA: receive 'SEN support' but there was no specialist assessment of type of need.

An EHCP may cease if the young person:

- dies;
- moves outside of England;
- moves on to higher education;
- moves on to paid employment excluding apprenticeship;
- no longer wishes to engage with education;
- reaches maximum age (25);
- has their special needs met without an EHCP;
- transfers to another LA;
- other reasons. (22)

In 2022, the number of EHCPs discontinued in the **City of London** was less than eight. (23) Likewise, the number of YP aged 16/17-years-old not in education, employment, or training (NEET) or had no known activity was also less than eight. (24)

In the same period, 82 plans were discontinued in **Hackney**. The main reason for a plan being discontinued in Hackney was the plan being transferred to another LA (77%). (23)

In Hackney, similarly to London and England, the proportion of YP aged 16 or 17-years-old who were NEET or had no known activity was higher among those with an EHCP (5%) compared to YP with SEN support (4%) and no SEN (2%). (24)

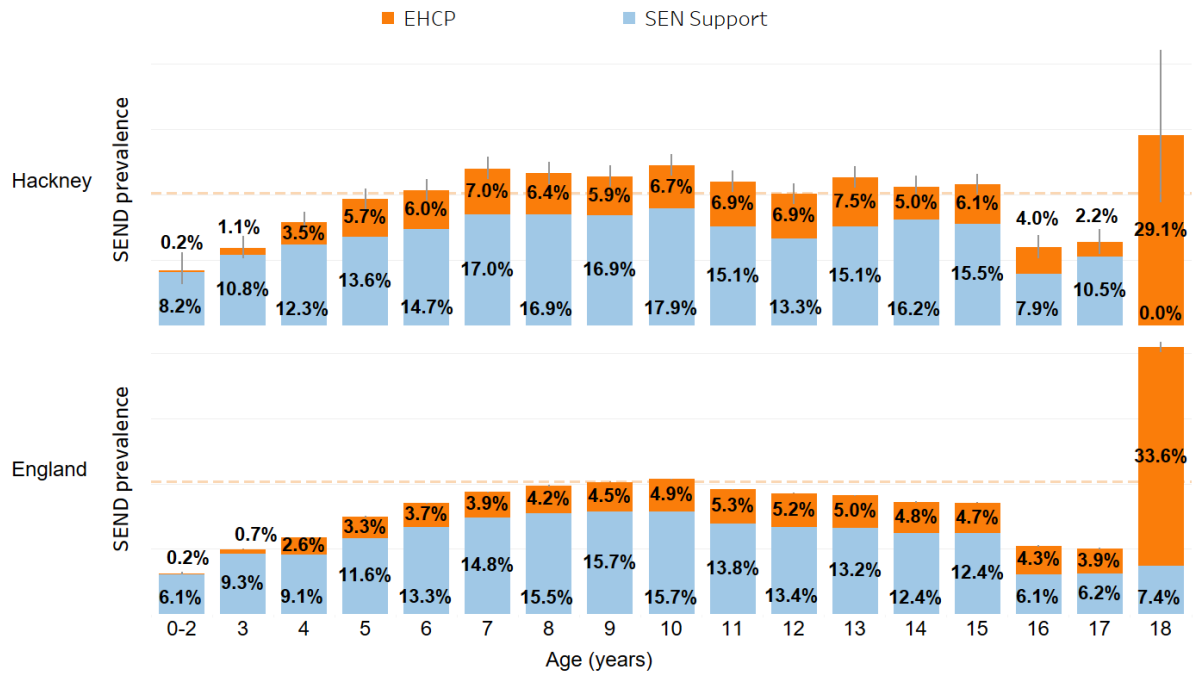
## **Socio-demographic characteristics of those with SEND**

### **Age**

SEND prevalence rises up to the age of 7 and stays relatively steady until the age of 10. After that, the prevalence declines, reaching a new stable plateau until the age of 15 (Figure 10). This coincides with secondary school age and is similar to England. (8)

Beyond the age of 16, the prevalence of SEND among YP significantly decreases both locally and nationally. However, in England the decline is more noticeable among those with SEN support while the proportion of those with an EHCP remains relatively constant. At 18, there are no more pupils with SEN support in Hackney (England figures show that there are 7.4% 18 year olds who had SEN support). There is a noticeable increase in the relative proportion of pupils with an EHCP in Hackney and England. (8)

**Figure 10. Prevalence of pupils with special education needs provision by age, Hackney, 2022/23**



Source: Department for Education, Special educational needs in England, Age and Gender, by type of SEN provision and type of need, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools and state-funded alternative provision schools. Does not include independent schools.

The dashed lines represent the overall prevalence of CYP with SEN support (14.6%) and this one summed with the prevalence of CYP with an EHCP (5.7%), totaling 20.3% of CYP with SEND.

SEN: special education needs, includes disabilities.

EHCP: education, health and care plans

## Sex

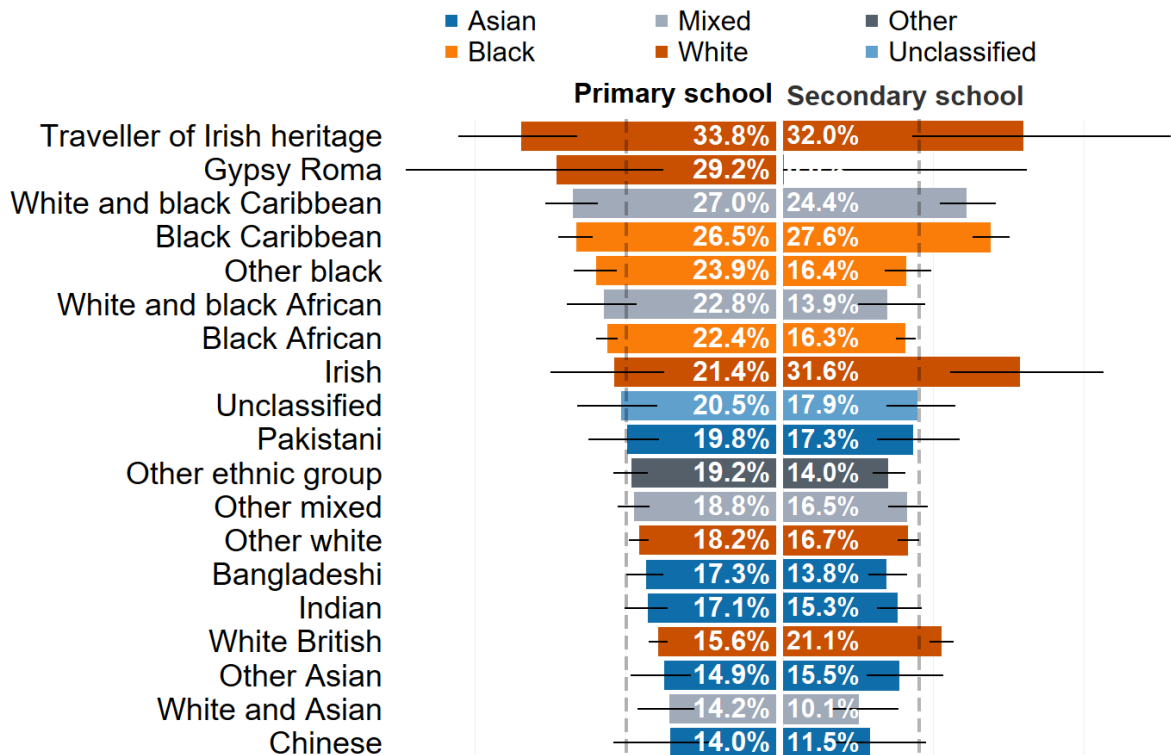
SEND was substantially more common in boys than girls attending primary schools, both in the City of London (31% vs 17%) and Hackney (26% vs 14%) in 2022/23. This was in line with the England average (21% vs 11%). (8)

The same pattern was observed for secondary school CYP in Hackney (24% among boys vs 14% among girls), and was also consistent with England's average (18% vs 11%, respectively). (8)

## Ethnicity

In 2022/23, the proportion of children with SEND was significantly higher among 'travellers of Irish heritage', 'white and black Caribbean', and all black ethnicities in Hackney's **primary schools** compared to the Hackney average (Figure 11). (8)

**Figure 11. Prevalence of pupils with special education needs by ethnicity in primary and secondary schools, Hackney, 2022/23**



Source: Department for Education, Special educational needs in England, FSM, Ethnicity and Language, by type of SEN provision and type of need, 2023.

Notes: Includes state-funded nursery, primary, secondary and special schools, non-maintained special schools and state-funded alternative provision schools. Does not include independent schools.

The dashed lines represent Hackney average prevalence of pupils with special education needs for primary (19.9%) and secondary (18.1%) schools.

As the numbers at the one primary school in the City of London are small, the same analysis is not possible for the City. (8)

At **secondary schools in Hackney**, there is a significantly higher proportion of SEND among CYP in 'Irish', 'black Caribbean', 'white and black Caribbean', and 'white British' ethnicities compared to the average in the borough (Figure 11). (8)

### Language

SEND prevalence was higher among English speakers than among speakers of other languages in both the City of London (28% vs 21%) and Hackney (21% vs 19%). This is also the case for London (19% vs 14%) and England (18% vs 13%). (8) This might not fully represent the languages spoken as professionals reported that some families record English as their main language even if they speak another language at home.

### Free-school meals

As free-school meals are typically provided to students from low-income families, it is an indicator of socioeconomic status. In 2022/23, SEND prevalence was higher among CYP eligible for free school meals than those not eligible in the City of London (33% vs



23%) and in Hackney (27% vs 16%). This aligns with the averages for London (25% vs 14%) and England (28% vs 14%). (8)

## Young people with SEND in the Youth Justice Service

Those known to the Youth Justice Service are more vulnerable to health and other risks. A [Youth Justice Health Needs Assessment](#) conducted in Hackney found information about SEND status for 352 young people (out of the 417 young people known to Hackney Youth Justice service examined in the report). Out of those 352, 46 (13%) had an EHCP and 202 (57%) had SEN support. Therefore, 70% of YP known to Hackney Youth Justice Service had SEND. (25)

Out of all 248 YP with SEND, 160 had a record of their primary education needs. Unlike the overall SEND cohort, social, emotional and mental health (62%) was the most prevalent type of SEND found among these YP, followed by moderate learning difficulties (24%) and speech and language and communication needs (23%). (25)

## CYP with SEND who are 'in need' or looked after

Some children are more susceptible to risks and adversities than others due to their social context, and require specialised support. 'Children in Need' are those children assessed and supported through children's social care who have safeguarding and welfare needs, and include:

- children on child in need plans (CIN) as well as other types of plan or arrangements;
- children on child protection plans (CPP);
- looked-after children (LAC);
- disabled children. (26)

Considering that all disabled CYP are by nature considered 'in need' (26), in 2019/20, out of the total of 1,385 'Children in Need' attending school in **Hackney**, around 46% had SEND. This is lower than London (48%) and England (47%) but higher than NEL (42%).

Focusing only on LAC in the same period, out of the total of 179 CYP that are looked-after in Hackney, the proportion of SEND (51%) is also lower than in London (57%) and in England (55%), but similar to NEL's proportion.

It is not known why there is a relatively low prevalence of SEND among 'Children in Need' and LAC in Hackney compared to the average in the borough, despite the borough having a higher SEND prevalence overall than London and England averages.

Among CYP attending school in the City of London, the number of 'Children in Need' is less than eight, so analysis is not possible. However, 27% of CYP with an EHCP maintained by the City had some statutory social care needs (LAC, CP or CIN).

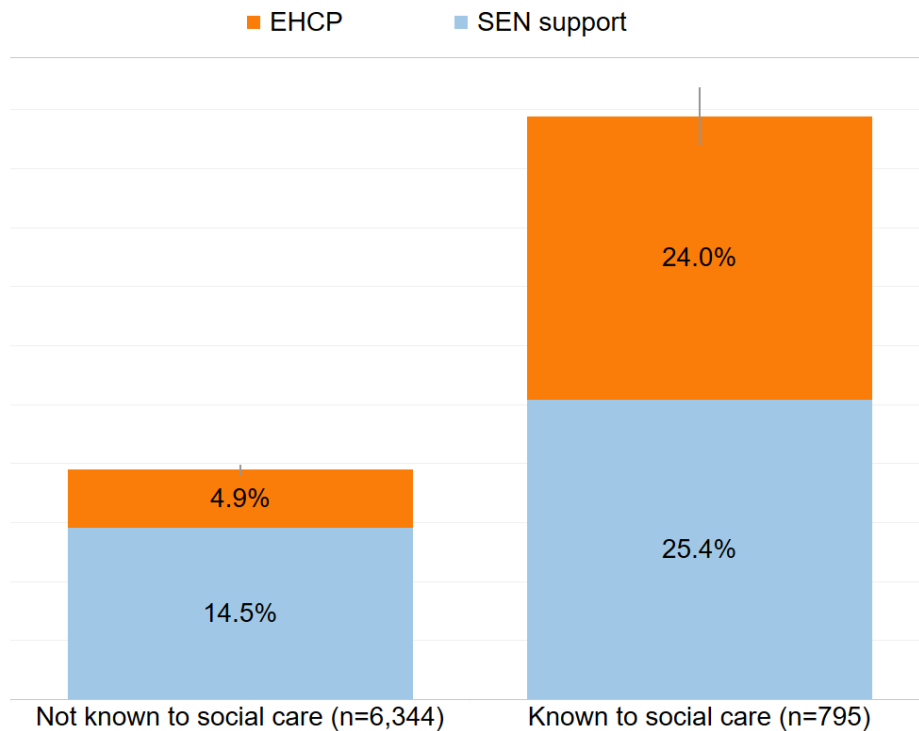
## All CYP known to Children and Families service (CFS)

Besides the statutory provisions already mentioned, CYP known to CFS can access non-statutory service provisions. These include:

- Early help, which provides holistic and wrap-around support for CYP who don't meet the threshold for statutory services but have some additional needs. Early help comprises:
  - the Multi-Agency Team, who coordinate early help for families who have children five or under
  - the Family Service, for families with older CYP
  - and Young Hackney, for young people.
- Youth Offending Teams work with young people involved in legal issues to assist them in staying away from criminal activities.

Among CYP going to Hackney schools, there were around 1,600 pupils known to Hackney CFS (around 5% of the total pupils), including non-statutory services in October 2023. This number included CYP living out of the borough but excludes CYP known to CFS in other areas. Almost half of those known to Hackney social care had SEN support or an EHCP, compared to around one fifth of those not known to social care (Figure 12). This shows the importance of partnership work between education and social care.

**Figure 12. Proportion of pupils by special education needs provision and whether they are known to Children and Families Services, Hackney schools, 2023**



Source: Hackney Education linked with Hackney Children and Families Services, extracted on 19/10/2023.

Note: The vertical lines represent confidence intervals, which are a way to estimate the range of values that we can be reasonably confident contain the true value we are trying to estimate.

Some CYP with an EHCP maintained by the City of London also attended social care services. For example, Short Breaks is a service in the City of London that provides fun and exciting activities for CYP with SEND away from their families. Short Breaks enable CYP with SEND to learn new skills and, at the same time, provide parents and carers with a much-needed rest from caring responsibilities. (27) This service was used by 41% of CYP with an EHCP maintained by the City of London.

Fewer than eight CYP with SEND registered with the one primary school in CoL were known to CoL social care. However, they may be known to social care outside the area.

# Chapter 5: Health and wellbeing needs

## Chapter Summary

**Availability of data on health needs of CYP with SEND**

Data on the health needs of CYP with SEND varied depending on the type of provision the CYP received, where they lived, and their school registry location.

	Registered in a school in City and Hackney	Living in City and Hackney and homeschooled or not registered in a school	Living in City and Hackney and registered in a school out of these areas
<b>Legend</b>			
🕒 Data on the primary special education needs from the school census			
⚠️ Limited health-related data in the EHCP due to inconsistency in the data recording			
✖️ Lack of data that matches pupils with SEN support and their health conditions			
<b>SEN support</b>	🕒	✖️	✖️
<b>EHCP maintained by City or Hackney</b>	🕒 ⚠️	⚠️	⚠️
<b>EHCP not maintained by City or Hackney</b>	🕒	Not applicable	Not applicable

**'Medical needs'**

Data on the health needs of CYP with SEND in both EHCP and service registries mainly focus on the primary educational needs. Other 'medical needs' mentioned include:

- epilepsy
- allergies
- eczema
- Down's syndrome
- asthma
- continence and constipation
- heart conditions

**Speech and language therapy (SaLT)**

SaLT was the most frequent service CYP with SEND attended. Although the number of referrals of CYP living in City and Hackney hasn't changed much from 2018 to 2023 (around 1,000 per year), the referrals made are more appropriate. Therefore, these children are more likely to start treatment at an earlier age.

**Looked-after children**

Local authorities must conduct health assessments for all looked-after children. CYP with SEND had poorer outcomes.

	SEND	No SEND
<b>Mental health as a concern</b>	58%	40%
<b>Oral health outcomes</b>	unknown	
<b>Vaccines up-to date</b>	35%	47%

Proportion of children and young people referred to speech and language therapy

Year	0-4	5-9	10-14	15+
2018	15.0%	27.9%	57.1%	0.0%
2019	2.1%	53.5%	26.2%	18.1%
2020	9.9%	57.6%	19.5%	13.0%
2021	21.8%	48.4%	17.9%	12.0%
2022	42.0%	31.4%	17.2%	9.4%
2023	58.0%	18.7%	14.7%	8.6%

Sources: Hackney Education, 2023. 'Medical need' recorded at Education, Health and Care plans maintained by Hackney. Homerton, 2024, Speech and Language Therapy service data. Special Schools Nursing Provision Report, 2024. London Borough of Hackney, 2024. Health assessment for children and young people who were looked after for at least 12 months

Data on the health needs of CYP with SEND is limited. While there is some data for CYP with an EHCP maintained by City or Hackney, limited data is available for those with SEN support registered in a school in the City of London or Hackney, and no data is available for CYP with SEN support registered in a school outside City and Hackney or not registered in a school. (Table 6)

**Table 6. Health data availability by sub-groups of children and young people with special education needs and disabilities, City and Hackney, 2023**

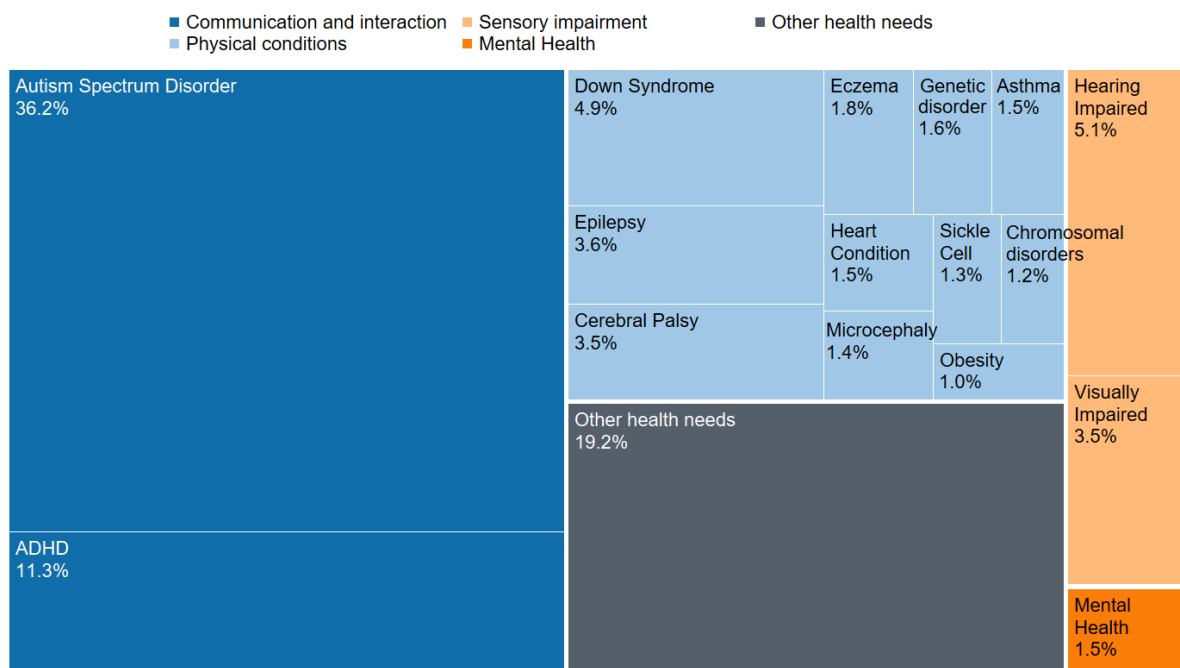
	<b>Registered in a school at City or Hackney</b>	<b>Living at City or Hackney and registered in a school out of these areas</b>	<b>Living in City or Hackney and homeschooled or not registered in a school</b>
<b>SEN support</b>	Data on the primary special education needs from the school census.	Lack of data that matches pupils with SEN support and their health conditions	Lack of data that matches pupils with SEN support and their health conditions
<b>EHCP maintained by the City of London and Hackney</b>	Data on the primary special education needs from the school census.  Limited health-related data regarding EHCP due to inconsistency in the way data are recorded.	Limited health-related data in the EHCP due to inconsistency in the way data are recorded.	Limited health-related data in the EHCP due to inconsistency in the way data are recorded.
<b>EHCP not maintained by the City of London and Hackney</b>	Data on the primary special education needs from the school census.	Not applicable.	Not applicable.

Source: Table prepared by the authors.

## Medical needs of CYP with an EHCP maintained by Hackney or City

Data obtained through the school census has already been presented in Chapter 3. Of the total 3,519 CYP with an **EHCP** maintained by Hackney, around 75% do not have any 'medical need' documented in the EHCP record. Among the 869 who did have a 'medical need' recorded, only one condition was listed per CYP. (9) However, this is unlikely to reflect reality as some CYP with SEND have severe complex needs. (28) The most commonly recorded condition was Autistic Spectrum Disorder, accounting for about one in three of all conditions, followed by ADHD at about one in 10. (Figure 13)

**Figure 13. 'Medical need' recorded at Education, Health and Care plans maintained by Hackney, 2023 (n=869)**



Source: Hackney Education, 2023.

Notes: Data extracted on 27/10/2023. Conditions affecting fewer than eight CYP were grouped as 'Other health needs'. 'Medical need' was the term used by Hackney Education.

## Services accessed by CYP with SEND

In addition to data held by the City of London and Hackney, different services that are accessed by CYP with SEND have information on their health needs. However, the data being collected varies with regards to consistency of data fields and levels of completeness, and most do not identify CYP with SEND within their own data systems. This prevents us from comparing the health needs of CYP with SEND with those of CYP without SEND.

## School Nursing

Local authorities are responsible for commissioning public health services for school-aged children including school nursing. (29) We were not able to obtain data from school nursing relating to the health conditions affecting all CYP or, indeed, CYP with SEND. This is because CYP's SEND and health conditions are recorded in free text fields and are therefore not easily extractable.

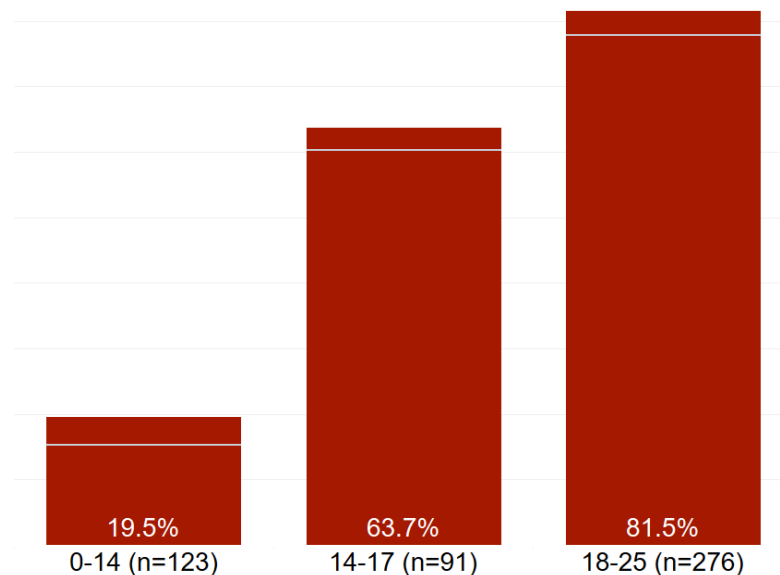
## Annual health checks for YP with learning disabilities

People with learning disabilities may have more difficulty in identifying health problems and accessing treatment, compared to the general population. Consequently, they are more likely have poorer health outcomes. (30)

To help reduce this health inequality, NICE recommends that all CYP and adults with a learning disability should be offered an annual physical health check. Despite NICE recommending annual physical health checks for people from all ages, NHS England has focused on delivering them to people over 14. (30)

The proportion of CYP with learning disabilities recorded by primary care in City and Hackney who had a health check and a health action plan done in the last 12 months, increased with age. The number is likely to be underreported. (Figure 14)

**Figure 14. Proportion of children and young people with learning disabilities recorded by primary care who had a health check and a health action plan in the last 12 months, by age group, City and Hackney, 2024**



Source: Clinical Commissioning Group, 2024

Notes: the bars represent the proportion who had a health check done in the last 12 months, while the horizontal line, the proportion who had a health action plan done in the last 12 months. Both metrics have as denominator the number of children and young people (CYP) with recorded learning disabilities indicated beside the respective age group.

Only CYP aged 14-17 were routinely monitored for these indicators and had data from 1st of May 2024. The additional age groups were extracted for this piece of work and are dated from 1st April 2024.

## Disabled Children's Service

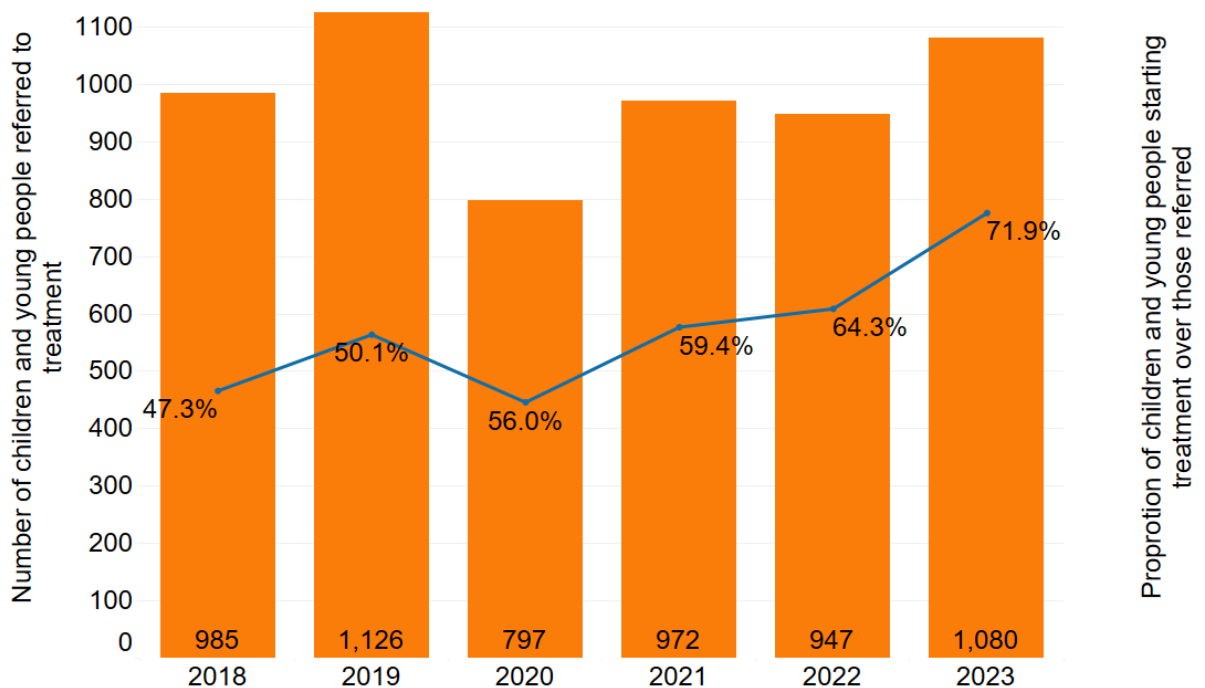
We have looked into the health and wellbeing needs of CYP known to the Disabled Children's Service, Visual impairment and Deaf and Partially Hearing Services. However, we were not able to find data for inclusion in this report. Details of the number of CYP known to these services are included in Appendices: 3, 4 and 5 of this report respectively.

## Speech and Language Therapy Service

The **SaLT service** is a joint service which works across Homerton Healthcare NHS Foundation Trust (Health) and Hackney Education (Education). The service provides interventions to develop the speech, language, communication, eating and drinking skills of CYP. It provides different levels of intervention, working closely with schools and other universal settings to identify needs early, and optimise the communication environment for all CYP.

Analysis of the SaLT service data found that the number of referrals of CYP living in the City of London and Hackney hasn't changed much over the last five years (around 1,000 per year). However, there was a noticeable increase in the proportion of those who started treatment out of the total CYP referred from 2018 to 2023 (Figure 15). All the CYP who are referred to SaLT have SEND.

**Figure 15. Proportion and number of children and young people living in City or Hackney who started Speech and Language Therapy treatment, 2018 to 2023**



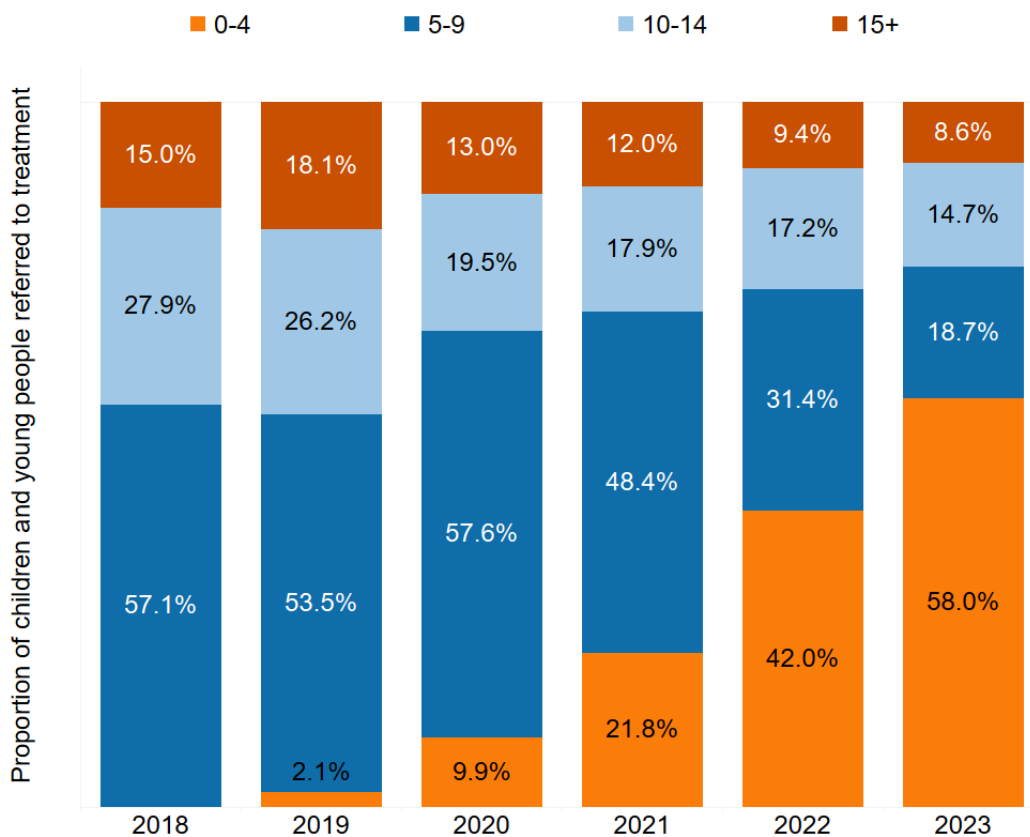
Source: Homerton, 2024



Over the last five years, the service has seen an increase in referrals for children under five years old (Figure 16). The referrals made are therefore more appropriate as these children are more likely to start treatment at an earlier age. The rise in referrals at younger ages might also reflect the increased need and complexity of cases after COVID-19, in line with what is seen nationally. (31) The service has also worked hard over a number of years to make sure that the wider workforce knows when to refer children for SaLT.

Children move from the Early Years Service to the School Service without needing a new referral. This, along with the support the service provides to pupils in school settings, may have led to the decrease in referrals for school-aged CYP.

**Figure 16. Proportion of children and young people living in City or Hackney referred to Speech and Language Therapy treatment by age group, 2018 to 2023**



Source: Homerton, 2024

## Hospital admissions

Some people with SEND are more likely to experience specific health conditions that lead to Emergency Department attendance or hospital admissions. However, the data available on Hospital Episode Statistics (HES) do not separately record if someone has SEND or not.

## Specific populations

### Looked-after children

Local authorities are responsible for making sure a health assessment covering physical, emotional and mental health needs is carried out for every CYP they look after, regardless of where that child lives. (32) LAC are given an initial health assessment upon entry into the local authority's care, which is then used to develop a health plan. This health plan is reviewed at least once every six months before a child's fifth birthday and at least once every 12 months thereafter. (32)

The local authority that looks after a CYP must take all reasonable steps to ensure that the CYP receives the healthcare services outlined in their health plan. This includes routine health checks from the universal Healthy Child Programme. (32)

As of 1st March 2024, 31% of the 262 CYP who had been looked after for at least 12 months in Hackney had SEND. The following data on mental health, oral health and vaccination uptake have been collected for this looked after CYP population (Table 7).

**Table 7. Health assessment for children and young people who were looked after for at least 12 months by special education needs status, Hackney, 1st March 2024**

	CYP with SEND	CYP without SEND
Completed Strengths and Difficulties Questionnaire (SDQ)	94%	94%
<b>SDQ indicated that emotional health and wellbeing was a cause of concern</b>	<b>58%</b>	<b>40%</b>
Had dental care assessment	62%	62%
<b>Result of dental care assessment</b>	<b>Not available</b>	<b>Not available</b>
<b>Have received all vaccination recommended for the age</b>	<b>35%</b>	<b>47%</b>

Source: London Borough of Hackney, 2024.

Note: Bold text indicates outcome measures.

- The **Strengths and Difficulties Questionnaire (SDQ)** is a concise emotional and behavioural screening questionnaire for CYP. Local authorities are required to administer the SDQ to understand the mental health needs of looked-after CYP aged between 4 and 16.
- The proportion of CYP who completed **dental care assessments** on time was similar for the looked-after CYP with SEND or without SEND. Unfortunately, the outcomes of these dental assessments are not available to the local authority, limiting our ability to evaluate the oral health of these CYP.

A dental health audit was carried out for LAC in Hackney, by the Designated Doctor and Nurse at City and Hackney, from NEL ICB in August 2023. (33) The audit found that of the 26 randomly selected health assessment records of looked after CYP, 50% of the CYP did not have a regular dentist; 31% did not have a known date of their last dental visit. 88% brushed their teeth twice daily with a fluoride toothpaste, 84.6% looked after CYP hadn't had their mouth checked by a LAC practitioner (either a doctor or nurse) and 31% did not have information recorded by the health professional regarding the condition of their teeth/gums/breath. An action plan has been drawn by the authors of the report based on the findings and a follow up audit will be carried out by March, 2025.

- The proportion of looked-after CYP with SEND in Hackney who **received all vaccinations recommended for their age** was low among CYP with SEND compared to CYP without SEND, which is well below the vaccination coverage levels in Hackney.

### CYP in Special schools

An internal report was prepared to assess the needs of CYP within the three Special schools in Hackney, and review if these needs are being appropriately met (34)

It shows that autistic spectrum disorders accounted for half of the reported health conditions that affected CYP in the three special schools in Hackney, followed by epilepsy and allergies (Figure 17).

**Figure 17. 'Medical needs' of the children and young people attending special schools in Hackney, Jan 2024**



Source: Special Schools Nursing Provision Report, 2024

Note: 'Medical need' was the term used in the report.

# Chapter 6: Stakeholder insights

## Chapter Summary

City of London and Hackney's Public Health Team carried out extensive stakeholder engagement with a total of 200 residents including young people with SEND, their parents and carers as well as 17 service providers during December 2023 to March 2024.

This chapter is divided into three parts. The first section covers insights from young people with SEND; the second section includes insights from their parents; and carers and the third section includes feedback from service providers.

The stakeholder engagement was conducted using qualitative methods such as interviews, focus group discussions and online surveys. As a non-random subset of the population were engaged, the findings will not be representative of the entire population. Additionally, there is likely to be a large degree of self-selection bias as respondents that are the most active in forums or meetings, and those that have had a negative experience of SEND services will have been more likely to participate.

The City insights have been excluded from this report as the number of responses were from a very small cohort of parents and carers and it wouldn't necessarily represent the experiences of the wider City CYP SEND cohort.

### Summary of findings:

**Young people with SEND:** Young people's perception of being healthy includes having nutritious food, good sleep, exercise and personal hygiene. Their perception of good mental health included engaging in art and creative activities.

### Parent and carers of CYP with SEND:

**Enabling factors** supporting health and wellbeing of CYP with SEND shared by parent and carers were:

- **Environment in early years and educational settings and support:** Parents valued the support provided by educational settings throughout early years and school age, to their CYP. They shared examples of different types of educational settings having a positive influence on their CYP's educational attainment and overall development. Support provided by the Education Team to CYP who are home schooled has also been reported as an enabling factor.
- **Parents and carers:** Parents and carers themselves play a huge role in enabling good health and wellbeing for their CYP with SEND as they are the main carers.
- **Training:** Training offered to parents and carers in supporting their CYP with autism was found useful.
- **Well coordinated services and timely assessment and diagnosis:** CYP with SEND are more likely to have better outcomes with regards to their health and

wellbeing needs when services are well coordinated and different service providers identify their needs at an early stage, with timely interventions offered. Parents appreciated when their CYP were diagnosed early and referred to the right services. Communication with parents from diagnosis to ongoing treatment or support was found to be a very important factor in meeting the needs of their CYP.

- **Social care support:** Parents and carers of CYP with SEND who were supported with social care services found it extremely useful.

**Areas of improvement** that will help CYP with SEND in maintaining their health and wellbeing were:

- **Communication, information and advice on SEND:** Feedback from both parents and services identified accessible, inclusive, clear and consistent information and advice on SEND, a key area for development. Making a visual map of the SEND pathway and services available would help families navigate them. Community networks used and trusted by parents and carers will be a useful way of disseminating information and advice on SEND.
- **Timely diagnosis of health and wellbeing issues:** 45% of parents and carers who participated in the online survey said that the health and wellbeing needs of their CYP with SEND were not diagnosed on time. Of the parents and carers from the Charedi community who took part in the online survey, 23% said that the health and wellbeing needs of their CYP with SEND were diagnosed at the right time, while over 36% parents were not sure.
- **Improved access to health services:** **Improved access** to GP and hospital services for both physical and mental health needs was a common theme during the engagement with parents and carers.
- **Improved knowledge on SEND amongst health professionals:** Parents and carers identified that there is a need for an improved understanding about SEND amongst health professionals.
- **Transition to Adult Mental Health Services:** Parents feedback reflected that there was a need to improve the experience of transition to Adult Mental Health Services for their CYP with SEND who were using mental health services.
- **Addressing the Impact of health on educational attainment:** Addressing the impact of health issues amongst CYP with SEND on their educational attainment and school attendance.
- **Social determinants of health:** Housing, transportation, sports, leisure and creative services were reported to be important determinants for maintaining good health and wellbeing for CYP with SEND. The majority of parents have requested an increase in the provision of leisure, play and creative activities for CYP with SEND. This has been identified as a huge gap in provision. Access to housing and transportation was raised as an area of improvement by some parents.

### **Service provider and professionals' feedback on factors affecting health and wellbeing of CYP with SEND and areas of improvement:**

- Feedback included school exclusions; higher need for special school places; access to health services; training for parents on understanding diagnosis and use of available resources; and supporting safe social interactions for CYP with SEND.
- Areas of improvement included improved referral and assessment timescales; supporting parents and family's wellbeing; mapping SEND pathway and services; greater engagement between stakeholders; addressing social determinants of health like housing, leisure and poverty; joint working through family hubs and neighbourhoods; and promoting annual health checks for YP with learning disabilities.

More details on the methodology, data collection tools, demographic information of participants who took part in the stakeholder engagement are provided in Appendix: 2.

## **Key Themes from Stakeholder Insights**

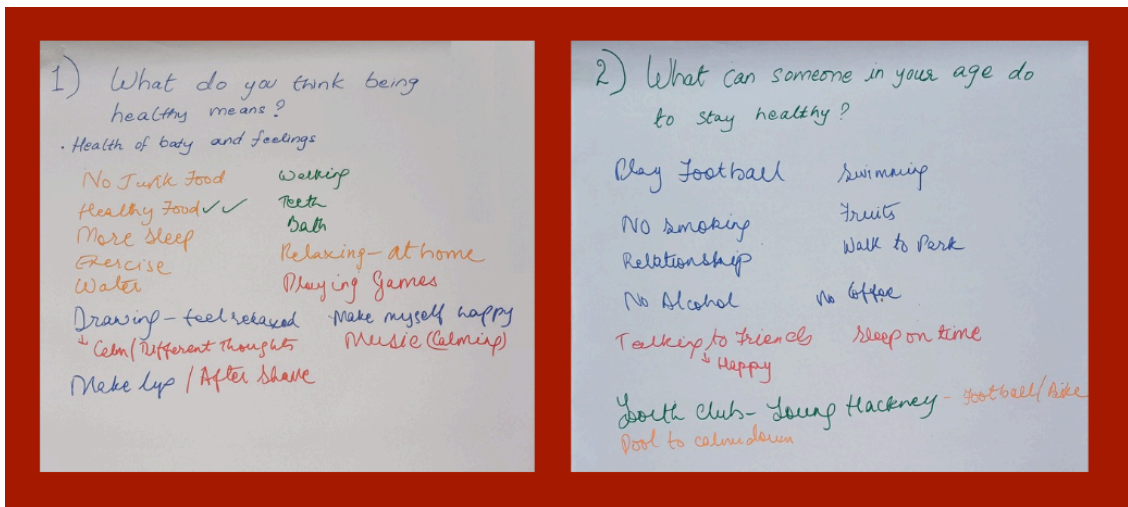
### **1. Children and Young People with SEND**

The responses from young people highlight their perceptions on physical and mental health (Table 8).

**Table 8: Young people's perception of being Healthy**

<b>Physical Health</b>	<b>Mental Health</b>
Nutritious Food	Playing games
Good sleep	Relaxing at home
Drinking water	Listening to music
Exercise - walking	Drawing to feel relaxed and calm mind from having thoughts
Personal hygiene - bathing, brushing teeth, aftershave, make up	

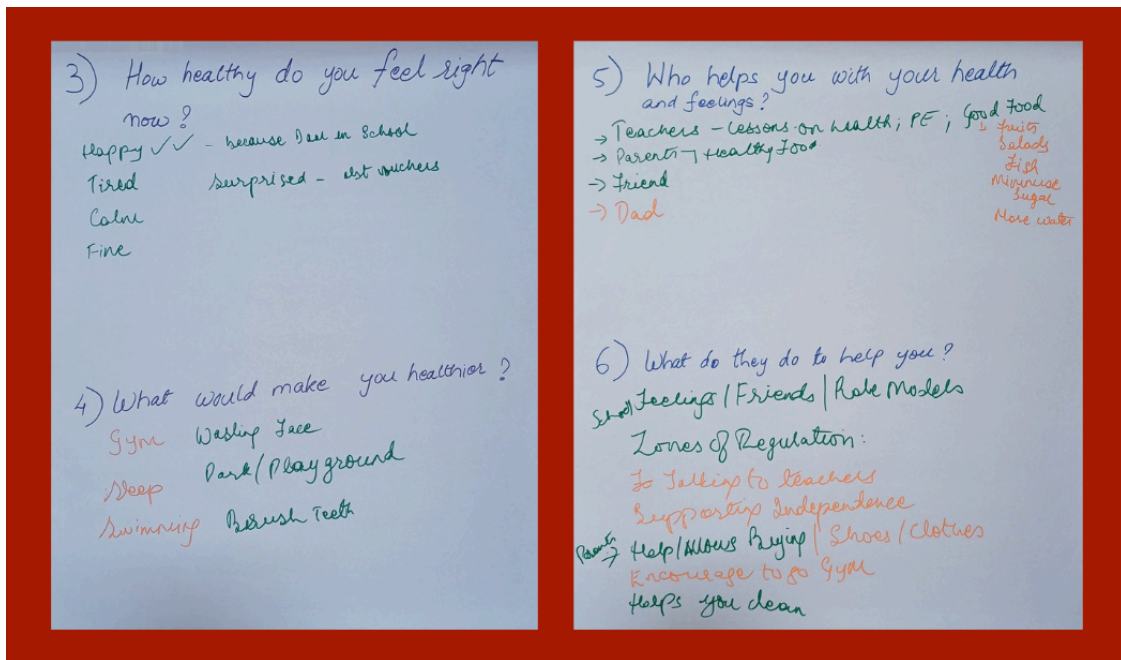
**Figure 18. Young people’s perception of being healthy and their lifestyle practices to stay healthy**



**Table 9: Young people’s lifestyle related practices to maintain their physical and mental health**

Physical Health	Mental Health
Being active: play football; swimming; walk in the park	Sleep on time
No smoking	Talking to friends
Eating fruits, salad, fish, minimise sugar, drinking more water	Attending youth club as it gives an opportunity to meet other young people and take part in football, bike riding
Tooth brushing	Swimming to calm down

**Figure 19. Who helps young people with maintaining their health and wellbeing and what do they do to help?**



**Table 10: Who helps young people with maintaining their health and wellbeing and what do they do to help?**

Who helps	How they help
<b>School teachers; Support workers; SENCOs</b>	<ul style="list-style-type: none"> <li>• Zones of regulation: everyday pupils are asked how they are feeling on the day when they come to school and they are able to share their feelings with a smiley/emoticon on a chart board in their classroom</li> <li>• Talking to teachers</li> <li>• Teachers support us to achieve our independence. Sometimes, by not helping us.</li> <li>• Having class lessons on health; physical education;</li> </ul>
<b>Parents</b>	<ul style="list-style-type: none"> <li>• Parents help us with basic needs such as food, shoes, clothes, encouraging exercise and helping us clean.</li> </ul>
<b>Health professionals</b>	<ul style="list-style-type: none"> <li>• Dentists - toothbrushing in schools; Nurse; Opticians were mentioned as offering all the relevant health services</li> </ul>
<b>Speech and Language team</b>	<ul style="list-style-type: none"> <li>• Communication</li> </ul>

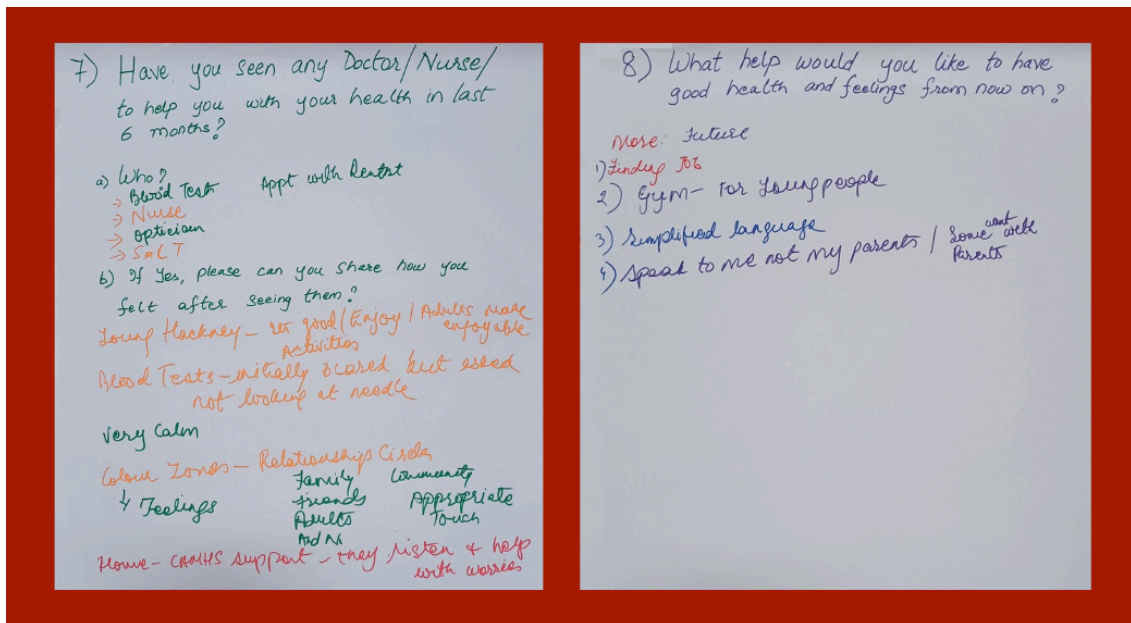


## CYP with SEND's Experiences of using health and wellbeing services

### Enablers

- Young Hackney Youth Centre: *it's good, enjoy activities being run by them.*
- Blood tests: *"Initially (I was) scared, but the nurse helps me calm down, for example saying not to look at the needle when my blood is taken."*
- Colour zones in schools help us talk about our feelings.
- *We also get to speak about the relationship circle that includes family, friends, adults, and community.*
- *"We talk about topics like appropriate and inappropriate touch when interacting with adults."*
- CAMHS support: *"they listen to me and help with my worries."*

Figure 20. CYP with SEND's experiences of using health and wellbeing services and their suggestions for future support



### Areas of improvement required to meet the health and wellbeing in future

- Support with finding a job
- Gymnasium for young people with SEND with a separate area where there are no adults
- Simplified language when communicating with CYP with SEND
- Training for professionals in using simple language and working with CYP with SEND
- Although some pupils said they were happy for the professionals to speak to their parents about their health, others expressed their wish to speak to them directly about their health and wellbeing.

*“Speak to me, not my parents. I need respect.” Young person about formal meetings with health professionals.*

*“Please use plain English while speaking with us.”*

## 2. Parent and carers of children and young people with SEND

### Parents view on Health and wellbeing needs of CYP with SEND in Hackney and the City of London

The responses highlight the range of individual children and young people’s needs within SEND, with a complex interplay of physical, mental, developmental and behavioural needs. This can entail need for specialist education, regular hospital visits, high levels of supervision, medications with side effects, and input from therapies including the Speech and Language Team, occupational and psychological therapies.

**Table 11: Health and wellbeing needs of CYP SEND identified by parents and carers**

<p><b>Physical health</b> epilepsy; deafness/hearing impairment; genetic disorders; mobility; seizures; eczema; hospitalisation due to allergies; cerebral palsy; Down's syndrome; poor dental health; lack of physical activity; difficulty with sleep; eating difficulties.</p>	<p><b>Mental health</b> low mood; self harm; anxiety; suicidal ideation; parental attachment; anxiety; body image and self-consciousness about weight; emotional distress.</p>
<p><b>Developmental</b> autism; ADHD; learning disability; non-verbal / speech and language needs; social communication difficulties; developmental delay; sensory processing disorders; emotional dysregulation; developmental delay; communication and speech; sensory issues.</p>	<p><b>Behavioural</b> disordered sleep Avoidant/Restrictive; Food Intake Disorder (ARFID), toileting; challenging authority; aggression.</p>
<p><b>Educational</b> challenges with reading and writing, unable to attend schools due to the impact of health issues</p>	<p><b>Other</b> complex health needs; gender dysphoria.</p>

*“When my daughter is angry she starts pinching herself or peeling nails. She's not hurting me. Then keep repeating the same thing with the legs and arms. She just hurts herself.”*

CYP health and wellbeing needs impact on parents who face additional parenting challenges with regards to providing support and managing outbursts.

*“It’s really frustrating and stressful, because he tires me mentally, and upsets me mentally.”*

*“My son has to be very careful what he eats, as he already ended up in hospital due to an allergic reaction. This is very hard for my son, as he is really young and has to forfeit treats.”*

*“My son gets frustrated quickly, as his speech is so unclear and it is therefore hard for him to be understood.”*

*“As he is becoming older he is more aware of his difficulties and that is affecting him emotionally”*

### **Enablers: Parents’ feedback on enabling factors for maintaining good health and wellbeing for CYP with SEND**

#### **School and the school environment**

Support from all staff in school and support received from schools were reported as enabling factors.

*“It has taken a couple of years but he now loves his secondary school and they have worked with me so much to understand his issues and behaviours.”*

*“My son was assessed at 5 years of age and his (mainstream) school was very helpful. The school Principal and SENCO supported to bring forward diagnosis within 6 months. He (son) has an Education and Health Care Plan and we are very happy with the support.”*

Special schools have also been mentioned as a positive influence, with parents reporting improvements in their children's wellbeing after transitioning from mainstream schools.

*“Since he started attending \_\_\_\_ (independent Special school) his physical development has improved”*

*Mainstream schools were not seen as helpful. “The mainstream school was not helping at all with none of his needs. (...) ... when I made a decision for him to come to a special school, things have been really good since.”*

*“Regular meetings with school to make sure his needs are met and kept safe”*

*“Independent Special School (.....) follow the program of therapies outlined for them and they give their utmost warmth and care.”*

Some parents from the Irish Traveller community found it helpful to have support from their CYP’s school. In general, parents said that they prefer their child to stay at home to prevent potential issues while interacting with others CYP and emotional health issues developing. They also valued teachers’ support with their child/young person’s reading and writing at home.

Waking hours curriculum allows the CYP with SEND in a residential setting to learn throughout the waking day, while taking regular breaks, and not just be limited to school hours.

### **Parents**

Most parents who participated in the engagements reported that they were the main carers for their CYP with SEND and this was an enabling factor for their CYP’s health and wellbeing.

### **Training**

The Early bird programme for parents with newly diagnosed children and young people with Autism Spectrum Disorders (ASD) has been found useful by parents. It is a course for parents of children with a diagnosis of ASD, providing information and strategies for families.

### **Well coordinated services**

CYP with SEND are more likely to have better outcomes with regards to their health and wellbeing needs when services are well coordinated and different service providers identify their needs at an early stage, with timely interventions offered. Parents appreciated when their CYP were diagnosed early and referred to the right services. Communication with parents from diagnosis and throughout the ongoing treatment or support was found to be a very important factor in meeting the needs of their CYP.

### **Timely assessment and diagnosis**

Timely assessment and diagnosis of SEND and health and wellbeing conditions leads to better development opportunities for the CYP and improved health outcomes. Parents and educational settings have been reported as playing the main role in identifying early signs of SEND.

### **Early intervention available once diagnosed**

*“He was given the diagnosis of ASD (Autism Spectrum Disorder) at 2 and a half (years of age), so a lot of early intervention was open to us.”*

*“After his diagnosis early interventions were introduced and immediately applied which helped my son a lot.”*

**Social care support package**

*“I finally got a carer to help in the evenings with bathing, teeth brushing, creaming, hair brushing and putting her to bed. It took a long time for the social care team to agree that I needed help but I am now so grateful for this support.”*

**Table 12: Parents and carers shared the following signs and symptoms to identify if their CYP’s health and wellbeing had become worse**

<p><b>Behavioural</b></p> <ul style="list-style-type: none"> <li>● change in behaviour</li> <li>● aggression and violence</li> <li>● withdrawal and social isolation</li> <li>● not wanting to leave home</li> <li>● sleep difficulties, nightmares</li> <li>● low motivation</li> <li>● increased Obsessive compulsive disorder (OCD) behaviours</li> <li>● changes in way of communication</li> </ul>	<p><b>Physical health</b></p> <ul style="list-style-type: none"> <li>● longer recovery from viral illnesses</li> <li>● more frequently unwell</li> <li>● increased seizure frequency</li> <li>● fainting and seizures</li> <li>● psychosomatic symptoms</li> <li>● fatigue</li> </ul>
<p><b>School</b></p> <ul style="list-style-type: none"> <li>● school avoidance</li> <li>● deterioration in school work</li> <li>● challenges with transitioning from holidays to routine school</li> <li>● poor concentration</li> </ul>	<p><b>Emotional and mental health</b></p> <ul style="list-style-type: none"> <li>● self harm and suicidal thoughts</li> <li>● emotional dysregulation</li> <li>● mood changes</li> <li>● stress</li> <li>● anxiety</li> <li>● panic attacks</li> </ul>
<p><b>Other</b></p> <ul style="list-style-type: none"> <li>● CYP able to tell parents</li> <li>● feedback from hospital team</li> <li>● Physical and emotional changes with age but CYP with SEND are unable to express</li> </ul>	

**Table 13: Services that help CYP with SEND**

<p><b>Parents/Family</b></p> <ul style="list-style-type: none"> <li>● Parents were often reported as the main source of support to CYP</li> </ul>	<p><b>Educational settings</b></p> <ul style="list-style-type: none"> <li>● early years and school staff</li> <li>● SENCO</li> <li>● welfare officer</li> </ul>
<p><b>Health and care professionals</b></p> <ul style="list-style-type: none"> <li>● family intervention worker</li> <li>● SaLT</li> <li>● educational psychologist</li> <li>● social services - short breaks, social care support package, carers</li> <li>● school wellbeing service</li> <li>● Spear programme via Hackney NEET</li> <li>● CAMHS</li> <li>● Hackney Ark</li> <li>● GPs</li> <li>● nurses</li> <li>● hospitals</li> <li>● dietician</li> </ul>	<p><b>Other services</b></p> <ul style="list-style-type: none"> <li>● VCSE organisations like Day-Mer, Children Ahead, African Community School, Carers forum</li> </ul>

**Areas that need improvement in maintaining good health and wellbeing for CYP with SEND**

**Health services**

**Delayed diagnosis**

Parents across the City of London and Hackney were asked if the health and wellbeing needs of their CYP with SEND were diagnosed at the right time, and 45% parents said they weren't diagnosed on time. 23% of Parents from the Charedi community said that the health and wellbeing needs of their CYP with SEND were diagnosed at the right time, while over 36% parents were not sure.

*"We lost 4 years that we could have been supported by the school or GP. She is really behind at school"*

*"Generally a healthy boy, but in the past, this has not been the case, and it has taken a while to identify what is wrong. Not taken seriously enough and could have been solved quicker."*

*"I suspected since she was 4 (years). The GP never got back to me when I contacted. At school I asked them at the beginning of year 1, if they could observe her and test her somehow and it took them 7 months to tell me I was right and something was going on, but the only thing they did was confirming my idea with the GP. So then it was when the GP put her on the waiting list for SCAC (Social Communication Assessment Clinic)."*

#### **Long waiting times for accessing GP services and hospital services**

*"We, the parents, make sure that our son gets the support he needs. It is not easy and we have to really push services when help is needed, but wait lists always make things harder."*

#### **Lack of knowledge amongst health professionals including psychiatrists**

*"I tried to get help from CAMHS but waiting lists for any meaningful intervention are far too long, and at least the professionals we saw weren't particularly knowledgeable about autism and ADHD (Attention Deficit Hyperactivity Disorder) and how these conditions can affect mental health in addition to external trauma."*

#### **Transitioning from children's services to adult health services**

Parents also reported that CYP with SEND are not seen as a priority particularly when they are in the transition age group.

*"My son said I'd rather go home and die rather than wait for this long in pain at the hospital (A&E)" There were no beds available. During every crisis situation, we offered acupuncture, massage to both my sons at home, but in this case it wasn't working. They needed more intervention. After waiting for five hours at A&E, I took them home, and their GP offered oral medication."*

#### **CAMHS and transition to Adult Mental Health Services (AMHS)**

*"They require professional therapy by a registered clinical and CAMHS have ignored our referral"*

*"My son was transferred by Specialist CAMHS services to a nurse at the age of 14 years and once he reached 16 years they discharged him back to the GP. There is nothing between 16 - 19 years, there is a gap in services. The GP continues prescribing the medication for MH issues but he needs more care."*

### **Schools and school environment**

#### **Missing school due to health issues**

*"He has difficulties which I believe could have been improved with timely physiotherapy and targeted exercises. At school he spent way too much time in 'isolation' when physical activity could have helped him calm down and progress."*

*"Our child has developed an anxiety driven chronic pain condition... We see this as caused mainly by his mainstream school, and Hackney's failure to provide the support*

*he needed, and fighting against his need for a special setting, and leaving him out of school for almost a year”*

*“[The Ark] gave him the statement and said he needs a lot of help but I had to make sure that he gets what he is entitled to.”*

*“Most children miss out on support until they win a long battle to get a EHCP. Families that are not well resourced financially, are not able to pay for legal fees for appealing following a decision that doesn’t support having an EHCP for their child or young person.”*

*“Although my boys have EHCPs and study in a mainstream school, it doesn’t meet their needs and it’s just on paper. Parents have to appeal and then the Council will be willing to discuss the needs of their CYP. They will try to push to see if I will give up.”*

### **Lack of Integration between services**

*“Due to his age, we have encouraged various early interventions and checks. However it took an acute service and hospitalisation at Great Ormond Street (hospital) to link up with various specialists and prioritise referrals to local services.”*

### **Social determinants of health**

Housing, transportation, sports and leisure services were reported to be important determinants for maintaining good health and wellbeing for CYP with SEND.

*“My son is 10 and still has to share a room with me”*

*“My son is lacking space to express himself in the hostel we have been placed in”*

*“It took 10 days for the boiler to be fixed in winter. Lack of communication from (Hackney Council) housing staff and no updates on status of service were not helpful with families like ours with two CYP with SEND.”*

The majority of parents requested an increase in the provision of leisure, play and creative activities. This has been identified as a huge gap in provision.

*“There is a shortage of art, craft, and creative activities for CYP with SEND.”*

Suitable housing came across as a crucial factor contributing towards health and wellbeing needs. Families living in private rented accommodations face challenges when landlords do not allow recommended adaptations. Referring such cases to organisations like Shelter indicates a need for advocacy and support in securing suitable living conditions. Parents also shared the need for effective and quicker responses to requests from families living in Council housing.

Transportation to and from the school was noted as both an enabler and an area which needed attention. Parents of CYP with SEND who attend special schools find it really



helpful having transportation provided by the school. However, CYP who attend mainstream schools mainly rely on parents/siblings/family members dropping them off and picking them up. Use of public transport posed challenges around accessibility, bullying and safety affecting CYP with SEND.

### ***Lack of support for employment in transition to adulthood***

*“Frustrated with unemployment and is in that category of almost no man’s land, just a little too old at 23, wanting to experience living on his own, and needing a skill or trade that almost guarantees him a job”*

### **Additional feedback relevant to specific communities in the City of London and Hackney**

In addition to the above themes from parent carer responses, there were a few themes specifically highlighted by some communities described below:

- **Parents from the Irish Traveller community**

One third of CYP with SEND from the Irish Traveller community, whose parents were interviewed, were homeschooled.

Most of the health and wellbeing needs, enabling factors and areas requiring improvements that have already been reported (above) were similar to those shared by parents from the Irish Traveller community. However, Irish Traveller parents shared the following, additional, specific challenges:

- Fear of labelling and community stigma
- Need for information in an accessible format for parents who can't read and write
- Misconceptions regarding the disproved link between vaccines and autism
- Need for greater engagement with Traveller parents
- Experience of discrimination
- Parents managing without any external help as don't want any involvement with the police or social care

*“The problem is, I don’t want her to be labelled but I know that by having the EHCP, it means that she will get the right support”*

*“You don’t want your child to be labelled, as you get that label and it affects them for life”*

*“They know Travellers have a lot of autism and they know that they can’t really read and write but they still give us lots of paper information that just goes into the bin. Interviewer: Who are they? The Health Visitor, they just come and give you information. They don’t really talk to you like before, when we had our own health visitor who used to come around and would know you. You could talk to them without being judged but now, nobody knows you.”*

*“The problem (is) everyone is just (racist) racism - they see a Traveller child and they just think (of) problems and don't even want to help. They think that he will leave school anyway at 11, so they don't even try to give them what they are entitled to. But I want my son to read and write. I want him to know about how to do this and that, how to start his own business... They forget about us because they think we are stupid and that it's even worse if your child has special needs.”*

*“I had to fight but now she's getting what she is entitled to and that's only because I educated myself as a parent. I had to go and learn and read up. I had to go into the groups, into the Facebook forums to get what she deserved and a lot of Traveller people don't do that. A lot of Traveller people don't even know how to read and write. I'm not good at reading and writing but I learnt. I learned to make sure that I gave my best to my child.”*

Parents valued health and wellbeing services that were offered by multiple agencies in the past, through the Children's centres. Parents reported that some of this has been discontinued and not often well coordinated.

*“You would be able to do everything - go and get the baby immunised, weighed and see the baby doctor. It's a shame that you can't do any of that anymore as that helped me be able to know what to do when I had concerns. Now, I be worried about this one (directs attention to younger child), I have to fight to get seen by someone, as you just don't know what or where to go”*

- **Parents from the Turkish and Kurdish community**

Language barriers and a lack of information and advice in accessible formats were additional issues raised by parents from the Turkish and Kurdish communities. There was a preference in receiving advice and information from trusted organisations like Day-Mer with regards to CYP with SEND. Regular information and advice surgeries by different services that were offered in the past at Day-Mer were found to be beneficial by parents, however these have stopped in the last few years.

Parents shared that they had to do their own research for supporting their CYP with SEND as information is not often available in accessible formats.

Building trust with the community came up as a common suggestion during the focus group.

*“When my daughter was 4 years old she was seen by First Steps (part of CAMHS offer) and I got worried that social services might get involved, so I withdrew her (daughter) from the service (First Steps).”*

Parents from this community also suggested considering self referral as an option into CAMHS without any social care intervention, thereby reducing a layer in the system and help expedite the process and receive timely interventions.

- **Parents from the African community**

Funding received by schools and health services was perceived as an important factor in the type and quality of services offered to CYP with SEND. This came out strongly during the engagement with parents from the African community.

There is a perception that the financial support received by Special Schools per pupil becomes a barrier to pupils being able to move on to other schools/settings, particularly in the transition age group. Some parents felt that Special Schools are not supportive of pupils moving on to other settings while they are still in the secondary school age group but want to move towards independence.

*“You have to ask for it yourself, if you don’t do anything. I fought for my son to go to college while continuing to go to Special School. Otherwise they will try to keep in the Special School. I said he is 17 years old now, he has to get to know the world from another side, because here (in the Special School) all the children are protected from everything.”*

*“I don’t want to rely on the government too much, I want my son to be independent and learn the skills and get work.”*

Some parents perceived that Academies accept CYP with SEND and receive the funding from the DfE, but don’t have the capacity to meet their needs.

*“EHCP doesn’t come easy, I had to fight for it, but after all the efforts, it is not being implemented by academies. I don’t know if they (Academy schools) are accountable to the Council”*

Parents expressed the need for Hackney Education to play a role in mediating between parents and schools.

A few parents have also reported that EHCPs do not get translated into implementation and don't meet their CYP's health and wellbeing needs. Parents also shared their frustration on the time taken to receive a EHCP for their CYP with SEND.

- **Parents from the Charedi community**

CYP with SEND from the Charedi community were more likely to attend an independent school as compared to the rest of the SEND cohort.

Parents from the community often mentioned their need to rely on private therapy and private tutors to support their CYP's health and wellbeing and learning needs.

*Therapeutic input: “she improved a lot lately due to intervention, more manageable now at home and at school”*

Charedi parents also mentioned receiving support across multiple services - education, healthcare, CAMHS and respite activities.

We noted parents' desire for support from clinicians from the same ethnic background. Many responses highlighted the need for Speech and Language Therapy and emotional therapy, quicker and easier access to support and longer, more consistent and affordable therapies.

*"Parents are there (to support), but she would do so much better with further support."*

**Table 14: Charedi parents expressed the need for future services to include the following**

NHS services:	Education:	Out of school activities and lifestyle
<ul style="list-style-type: none"> <li>● Speech and language therapy</li> <li>● Emotional therapy</li> <li>● Occupational therapy</li> <li>● Psychiatric assessments</li> <li>● CAMHS</li> <li>● Hearing impairment support</li> </ul>	<ul style="list-style-type: none"> <li>● More specialist sessions and school support</li> <li>● Specialist teaching</li> <li>● One to one teaching support</li> <li>● Behaviour specialist</li> <li>● Training on social skills and relationship building</li> <li>● Increased therapy at school</li> <li>● 1:1 mentorship</li> </ul>	<ul style="list-style-type: none"> <li>● After school and outside school</li> <li>● Exercise</li> <li>● Music</li> <li>● Pet therapy</li> <li>● Play therapy</li> <li>● Healthy lifestyle programmes</li> <li>● Peer support for CYP</li> </ul>

### **3. Provider and professionals' feedback on the Health and wellbeing of CYP with SEND**

#### **Health and wellbeing needs of CYP with SEND**

Professionals and service providers highlighted that it can be difficult to generalise the health and wellbeing needs of CYP with SEND. This is due to variations in different special educational needs or disabilities as well as the effects of demographic factors such as age, gender and ethnicity.

Nonetheless, themes emerged on physical health, mental health, behaviour and communication issues, access to services and adequate training, as well as the social determinants of health such as housing.

Providers mentioned the following additional areas of need amongst CYP with SEND which were not included in parents' feedback.

**Table 15: Providers' feedback on needs of CYP with SEND**

<p><b>Education</b></p> <ul style="list-style-type: none"> <li>● reduced school exclusions</li> <li>● more Special School places</li> <li>● adjustments in education</li> </ul>	<p><b>Access to services</b></p> <ul style="list-style-type: none"> <li>● timely diagnosis</li> <li>● access to GP/Dentist</li> <li>● advocates to help parents access services for their CYP</li> <li>● access issues for CYP who cannot attend a setting or CAMHS appointments</li> <li>● fundamental health matters need to be made accessible and manageable for families</li> <li>● speech and language</li> </ul>
<p><b>Training</b></p> <ul style="list-style-type: none"> <li>● parental psychoeducation about disability</li> <li>● support for understanding diagnosis</li> <li>● empowering the whole family to support the CYP and feel confident to use the tools/resources</li> </ul>	<p><b>Social interaction</b></p> <ul style="list-style-type: none"> <li>● staying safe online</li> <li>● healthy relationships</li> <li>● social communication needs</li> <li>● inclusion and opportunities for social interactions</li> <li>● equality, empathy, self confidence</li> </ul>

Providers who responded to the survey deliver the following services for CYP with SEND when asked the question: **What support does your organisation/team offer to children and young people with SEND with regards to their health and wellbeing?**

**Table 16: Services offered by respondents who work with CYP with SEND**

<p><b>Education</b></p> <ul style="list-style-type: none"> <li>● PSHE sessions to all YP with SEND</li> <li>● Sensory rooms and resources</li> <li>● Zones of regulation</li> <li>● Makaton sign support</li> </ul>	<p><b>Physical Health</b></p> <ul style="list-style-type: none"> <li>● Targeted Health Outreach Service for YP 14-19 years not eligible for social care services and social workers.</li> <li>● Health action plans</li> <li>● Support with accessing health, fitness and leisure activities</li> <li>● Young Hackney integrated early help and prevention service CYP 6-25 years</li> <li>● Young Hackney health and wellbeing service</li> <li>● Oral health</li> <li>● Tier 2 weight management service</li> <li>● SaLT universal service</li> <li>● Supervised Toothbrushing programme</li> </ul>
<p><b>Mental Health</b></p> <ul style="list-style-type: none"> <li>● Working in partnership with MASH and other mental health teams</li> <li>● Referrals to First steps, mentoring and small group support</li> <li>● CAMHS - diagnosis, and support for behaviour, mental health and emotional wellbeing</li> <li>● Therapist support</li> </ul>	<p><b>Training and support</b></p> <ul style="list-style-type: none"> <li>● Staff education on physical and health needs of CYP with SEND</li> <li>● Transition to adulthood</li> <li>● Advice and strategies on physical access to education</li> </ul>

### **Referral system and timelines**

There was a mixed response from providers on the referral system and how they promoted their services amongst families with CYP with SEND. Some services were open to self referrals, whereas others were through professionals with a set timescale and pathway for assessment and diagnosis.

Providers reported that the current waiting time for a mental health needs assessment was unacceptably high (6-10 weeks for assessment of mental health need, but about a year or more for neurodevelopmental diagnosis). Whereas for an autism diagnosis, the waiting time was approximately 18 months.

The timescale for an Education, Health and Care needs assessment is 20 weeks. While the timeline for EHCP was 6 weeks from receipt of E3 request to complete the EHCP report. The treatment time scale is based on goals set for the individual CYP. The main barriers faced by service providers in meeting the assessment, diagnosis and treatment timelines were:

- Limited capacity - small team with lots of 1:1 work and in the community
- Lack of understanding of services amongst parents and families
- For assessment/diagnosis: staffing, clinic space, absence/sickness, demand outstripping capacity, inadequate time to complete assessments
- For treatment/intervention: complex work for clinicians, too few staff, limited time for intervention work
- Slow referral pathways
- Long waiting lists for treatment

### **Areas of improvement suggested by service providers and professionals**

#### **Supporting parents and families' wellbeing**

*"More education and support for families."*

*"Support around family members who live with children with a diagnosis."*

*"Neurodiverse training for siblings of children with SEND"*

*"Supporting parents' wellbeing through the diagnosis process will better equip them and their parenting"*

*"We can support the parents to understand and work with their child's additional needs and look for national organisations for information"*

#### **Mapping SEND pathway and services**

*"So many gaps... Part of what creates the gaps is that there is not a map that provides the information to support families from diagnosis to adulthood. What to do, what support there is for the child and their families. This should be mapped out in tandem to support equal access for all."*

*"Inadequate provision at Early Help/Getting Help"*

#### **Lengthy wait times**

*"Lack of mental health support with long waiting times."*

*"Wait times for autism assessments seem long and the appropriate support thereafter limited, similarly wait times for MH support for all young people including those with SEND seems to be a challenge. Young Hackney receives a significant number of referrals broadly related to both of these sets of needs"*

*"Young people without a learning disability are waiting for an autism assessment from Social Communication Assessment Clinic (SCAC) at Hackney Ark. I understand this is currently being addressed by First Steps which is fantastic."*

*“There are long waiting lists for Speech and Language Therapy, Complex Communication Clinic..., so it would be preferable for these to be reduced. However, my service bridges the gap in some ways by providing education and parenting support for the parents”*

**Greater engagement between stakeholders (for example between schools and community organisations)**

*“I would like to see more engagement with us from the SEN schools - I feel that we have a lot to offer and it is being missed by most schools”*

**Social determinants of health**

*“Need to factor in specific support for SEND with regards to housing, poverty and the multiple disadvantages faced when having a child / young person with SEND.”*

*Housing: “so many families are in cramped, small accommodation with other issues (E.g. mould) which is not suitable for CYP with SEND and contributes to parental stressors and wellbeing of the whole family including siblings”*

**Youth activities and services**

*“The youth offer for disabled children and young people is VERY sparse and poorly communicated. This limits social opportunity, friendships development and developing independence.”*

*“We would like to be able to offer more specific activities and groups (including participation groups) for children with speech, language and social communication needs including autism.”*

**Complex needs**

*“Those CYP whose anxiety is so significant that they are unable to leave the home and attend appointments with professionals. Their needs become exacerbated and entrenched. What about young people who can be dysregulated, aggressive and assault staff in Special Schools - not sure what can be provided for them - either via social care or CAMHS, particularly if the YP (young person) does not attend appointments.”*

**Weight management**

*“Obesity is a huge issue”*

**Health checks for YP 14+ years with LD and ASD**

*“Promote the Learning Disability and ASD Health Checks for young people who are 14+ years and registered on GP lists is eligible for this check. The numbers for YP accessing this offer are low. This can potentially be promoted by the school nurses.”*

**Joint working through Family hubs and Neighbourhoods**



*“ Paediatricians are keen to engage in more preventative and educational work e.g. allergy / asthma. There is also a project (partly driven by NEL) to think about Child Health Hubs in Primary Care where more care could be moved from acute to community settings with support for GPs.”*

*“I think being part of a Neighbourhood team could really facilitate a lot of the things. Co-locating office space with others who provide support to that Neighbourhood would build trust and links. When there are broader family issues identified, links and referrals could be made to the Neighbourhoods MDMs where whole families can be discussed. Also the School nurse Neighbourhoods team would get to know the facilities and VCS groups in that Neighbourhoods and could make links, be involved in addressing the broader public health issues for that Neighbourhood, be part of the Neighbourhood Team Meetings, VCS Forums, Leadership groups etc as they develop.”*

# Chapter 7: Recommendations

The following recommendations are predominantly based on the feedback from young people with SEND, their parents and carers, and system partners engaged as part of this needs assessment.

Work is currently underway to refresh the City of London and Hackney SEND and Alternative Provision strategies. Therefore, the recommendations from this health needs assessment will support this strategic work and the development of specific action plans for their implementation.

## 1. Communication, information and advice

- **Inclusive, clear and consistent communication and information for CYP with SEND and their parents/carers** in accessible formats, in community languages. A map of SEND pathways and services - from diagnosis to adulthood - would help parents and carers navigate the range of education, health and care services.
- **Improved and ongoing communication with professionals embedding respect, empathy and compassion from professionals** offering education, health and care services would improve service user experience. It will also provide opportunities for parents/carers to input into their care and enable services to be more tailored to their needs.
- **Regular dissemination of inclusive and culturally appropriate information and advice on SEND services through trusted organisations.** VCSE organisations and informal networks are key assets that should be resourced and supported to arrange regular information and advice surgeries for parents and carers.
- **Formalise the important role parents and carers play in co-production and peer support/ peer navigation by** supporting parents to become paid peer mentors or parent advocates, based in the community. Communication material, health and wellbeing workshops for CYP (offered in schools as part of PSHE and RSHE) should be codesigned with parents to ensure that parents' lived experience is embedded.
- **A holistic approach needs to be used when offering services** to ensure CYP with SEND and their families receive a one stop offer. Children and family hubs will be a great opportunity to achieve this.
- **Single point of contact (Hackney):** Parents really valued the continuity of support in early years and primary school, as there was a single person whom they could communicate with for any information/guidance. However, when transitioning to secondary school, parents feel lost due to the absence of a named person to contact for guidance/information. Similarly, for CYP with SEND being supported by social workers, having a named social worker would help resolve issues and delays in accessing social care services.

- **Single Point of Contact (City of London):** Parents in the City of London greatly appreciate the continuity of support provided by the Early Years Team during their children's transition from early years to primary school. Having a single point of contact for communication ensures that they can easily access information and guidance. Additionally, the availability of a dedicated officer for one-on-one sessions further empowers parents, offering personalised assistance as needed. This support helps parents make informed choices about both primary and secondary schools. Overall, this approach fosters confidence and clarity for families navigating the school transition process.

## 2. Diagnosis and early intervention and relevant referrals

- **Information and training for parents, carers and families on the signs of developmental delays** in CYP will support more early identification of SEND. Training about different types of SEND for parents upon diagnosis and services available to support them would also be helpful.
- **Training for all health, care and educational professionals** a) to develop a better understanding of the needs of CYP with SEND; b) to ensure services are offered in a culturally sensitive manner and; c) to improve the awareness of the local offer and support families navigate the system.
- **Improve the uptake of the 6-8 week reviews by Health Visitors** to be in line with the national target of 70%.
- **Promote and increase the uptake of free annual health checks** for YP above 14 years, with a learning disability. This will help identify any unmet health needs that wouldn't otherwise be recognised and provide relevant treatment and support.
- **Seamless referrals between different services for CYP with SEND** is crucial for better health and wellbeing outcomes and CYP with SEND achieving their full potential.

## 3. Access to services

- **Timely access to services** through reducing waiting times.
- **Offer seamless health and care services to YP with SEND transitioning to adulthood / adult services.**
- Use premises of closed mainstream schools in Hackney to **provide education for six forms/adults with SEND** where possible.
- **Offer tailored services** based on the varied needs of CYP with SEND across all age groups.
- **Develop a one stop service offer for CYP with SEND at the City of London.** This will ensure improved access for CYP with SEND as a result of reduced travel time and efforts coordinating between different services.

## 4. Addressing inequalities

- Ensure the **same level of service is offered to CYP with SEND with similar needs**, irrespective of where they live, which school they attend or which race or ethnicity they belong.
- **Ensure the health and wellbeing needs of CYP with SEND that are not in an educational setting are addressed**, including those who are homeschooled, not attending schools due to Emotionally Based School Non Attendance (EBSNA) or for medical reasons and/or are unable to leave the home and attend appointments with health care professionals.

## 5. Data and records

- **Improve data collection and recording of health and wellbeing needs of CYP with EHCP** to ensure better planning of services across education, health and care.
- **Develop data sharing agreements between health, education and social care services.** It will improve the service experience of CYP and their families, avoiding repeating the same information at each point of contact. It will also help have a fuller understanding of the health needs of CYP SEND and plan need-based services.
- **Plug the data gap on the health and wellbeing needs** of CYP with SEN support, those who are homeschooled (without an EHCP) or registered in an educational setting outside of the City of London and Hackney (without an EHCP). This will give us a full picture of the health and wellbeing needs of the entire cohort of CYP with SEND and plan services to meet their needs.

## 6. Addressing social determinants of health and wellbeing

- **Housing:** Improve access to suitable council housing for CYP with SEND by reducing waiting times. Offer guidance, advice and advocacy support for families with CYP with SEND to help address the housing challenges faced by those in private rented accommodations.
- **Transport:** Consider providing transportation from home to school for CYP with SEND in mainstream schools based on their needs.
- **Improve and expand the leisure and creative services offered:** For example by making all leisure places inclusive for those with SEND and reducing the long waiting times to access adventure playgrounds for CYP with SEND in Hackney.
- **Social care:** Reduce delays in payments from Hackney social care for short breaks and increase in the number of hours offered for short breaks.

# Appendix 1: National and Local Policies

## National policies

This chapter covers the key policies and evidence that serve as a guide in designing and delivering services and interventions for CYP with SEND.

**Table 17: National Policies**

<p><b>Children and Families Act (2014):</b> The Children and Families Act 2014 includes in depth guidance and requirements for local authorities in chapter 3 for children and young people with special educational needs or disabilities. (35) . The Act states that a child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her. It further states that a child of compulsory school age or a young person has a learning difficulty or disability if he or she has a significantly greater difficulty in learning than the majority of others of the same age, or has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for other of the same age in mainstream schools or mainstream post-16 institutions.</p> <p>Local authorities have a responsibility for a child or young person if he or she is in the authority's area and has been a) identified by the authority as someone who has or many have special educational needs, or b) brought to the authority's attention by any person as someone who has or many have special educational needs. Local authorities are responsible for integrating education, training, healthcare, and social care where this would promote the wellbeing of young people with SEND. The Act requires local</p>	<p><b>Care Act (2014):</b> The Care Act includes detailed requirements for local authorities to provide care and support to children transitioning to adult care. For a child that is likely to have needs for care and support after becoming 18, the local authorities are required to assess whether the child has needs for care. The needs assessment requires involvement of the child, the child's parents and any carer that the child has and any person whom the child or a parent or carer of the child requests the local authority to involve. (36)</p>
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<p>authorities and partner commissioning bodies to put in place joint commissioning arrangements in order to plan and jointly commission the education, health and care provision for children and young people with SEND.</p> <p>The act included two key changes: it extended support for children and young people with SEND in the age group of 0-25 years and introduced new EHCP replacing the SEN statements.</p>	
<p><b>The SEND Code of Practice 0-25 years (2015)</b> provides statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities. The broad areas of need are set out in the SEN Code of Practice 2015, Chapter 6 are listed below: (22)</p> <ul style="list-style-type: none"> <li>● Cognition and Learning</li> <li>● Communication and Interaction</li> <li>● Social, Emotional and Mental Health Difficulties</li> <li>● Sensory and/or Physical Needs</li> </ul>	<p><b>NICE Guidance (NG43 -2016)</b> provides guidance on the transition from children's to adults services for young people using health or social care services. (37) It aims to improve the experience of transitioning into adult health and social care for YP and their carers.</p>
<p><b>Government SEND Review 2023:</b> SEND and Alternative Provision Improvement Plan, Right support, Right place, Right time (2023) outlines a number of changes and approaches to SEND delivery. This plan was published by the government in response to the Green paper in March 2023 and will focus on: a) fulfilling children's potential: b) build parents' trust and c) provide financial sustainability. It sets out new evidence-based National Standards that will improve early identification of needs and lays out clear expectations for support to be available in mainstream settings. It also includes having standardised EHCPs and launching applications from Local Authorities for opening new special free schools. (38)</p>	<p><b>The Children's Commissioner of England report 2023:</b> focused on the experiences of disabled children that included children with autism and other neurodevelopmental needs, additional social and emotional needs as well as physical needs. The report noted a gap in consistent and centralised data on the number of children in England who are disabled owing to different definitions of disability. The report enlists key barriers faced by disabled children which includes late diagnosis of needs, schools' inability to meet the needs of children with additional needs, inaccessible activities, poor quality of care, bullying and discrimination, disruption in services during transition, lack of whole family approach. Key recommendations of this report included: a)</p>

	<p>To be understood, seen and heard with improved early identification, better data, access to advocacy being key areas of improvement: b) Good education and support in schools; c) Accessible activities; d) High quality care; e) Freedom from harassment and discrimination; f) Smooth transition and preparing for adulthood; and g) A whole family approach. (39)</p>
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## Local Policies

**Table 18: Local Policies**

<p><b>Hackney Young Futures Commission 2019:</b> An independent Young Futures Commission was set up in 2018 with funding from Hackney Council to understand young people’s lived experiences in the borough, over a 2 year period. The Commission carried out a consultation amongst 2,500 young people in the age group of 10-25 years and published a report ‘Valuing the future through young voices’. Key themes that emerged from the consultation were: a) A bright future; b) A secure future; c) An active future; d) An inclusive future: e) A safe future; and f) A healthy future. (40)</p>	<p><b>SEND Strategy City of London (2020-2024):</b> City of London’s SEND strategy for 0-25 year olds aims to provide an inclusive and safe environment where children and young people can learn, achieve and participate with other children and young people. The three key outcomes to be achieved by the strategy are: a) having a robust and multi-agency approach in identifying, assessing and meeting the needs of children and young people with SEND; b) all children and young people with SEND are well prepared for and have successful transition to adulthood; and c) children and young people with SEND are integral and valued members of the City of London community. (41)</p> <p>The City SEND strategy is being refreshed and engagement is being carried out at the time when this report was written.</p>
<p><b>Hackney’s SEND Strategy 2022-25:</b> The Hackney SEND Strategy lays out four key priorities: a) Outstanding provision and services; b) An earlier response; c) Preparing for Adulthood and d) Joining up services. Hackney’s vision is to provide an excellent, inclusive and</p>	<p><b>The Hackney Preparing for Adulthood Strategy (2024-2027 unpublished at the time of writing this report)</b> will be delivered through a number of objectives sitting under four key priorities. The priorities are to:</p>

<p>equitable local experience for all Hackney CYP with SEND. (42)</p>	<ul style="list-style-type: none"> <li>● actively seek and listen to the views of young people and their families to learn from and improve their experiences of transition to adulthood</li> <li>● collaborate as a system-wide partnership to develop clear and strong shared transitional pathways that start at the earliest opportunity and support the four mandated PfA outcome areas.</li> <li>● provide clear and accessible information for CYP and their families to enable them to better understand and navigate the transition from childhood to adulthood</li> <li>● identify opportunities for joint commissioning arrangements across children's and adults' services that better support young people's transition to adulthood.</li> </ul> <p>Year 1 of the delivery of the strategy will focus on transition pathways development work. (43)</p>
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# Appendix 2: Qualitative Methodology, Demographic distribution and Data Collection Tools

## Qualitative methodology used in gathering stakeholder insights

### A. Children and young people with SEND

- A focus group with **10** young people aged between 14 and 18 years was conducted at a Special School with the support of 4 school staff.

### B. Parents and carers of children and young people with SEND

- **Parent and carer survey**

- a) **90 parents and carers (5 City of London parents and 85 Hackney parents)** from the City of London and Hackney responded to the survey.

- b) A separate parent and carer survey was conducted amongst the Orthodox Jewish community and **60 parents and carers** responded. Children Ahead, a charity working with the Orthodox Jewish community supported with gathering and inputting parents' responses to the survey. Parents had an option to share their contact details at the end of the survey for further contact by the team.

- **Parent interviews**

- a) **3 interviews with parents** in the City of London from the Bangladeshi community were conducted with the support from The Aldgate school, City of London.

- b) **9 interviews with parents** from the Irish Traveller community were conducted with the support from the Traveller Housing team and Traveller Education Coordinator in Hackney.

- **Parent and carer focus groups**

- We conducted focus group discussions with **38 parents and carers** representing different communities and forums enlisted below:

- a) Parents and carers from the Turkish and Kurdish community with the support of Day-Mer Turkish and Kurdish Community Centre; a charity working with the Turkish and Kurdish community based on Hackney

- b) Parents and carers from the African community with the support of African Community School, which is a charity supporting children and young people with education.

- c) Hackney Parent Carer Forum
- d) City Parent Carer Forum
- 3) Hackney Special School

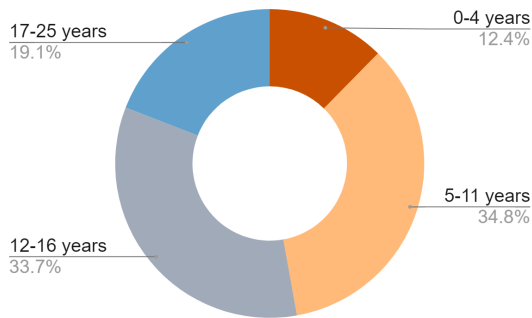
**C. Service providers**

We received **17** responses from the following **8 service providers**:

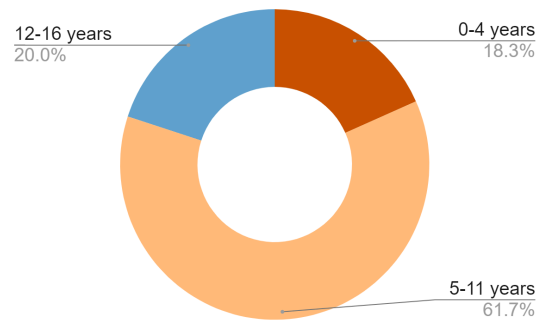
- Young Hackney Health & Wellbeing Team
- Homerton Healthcare NHS Foundation Trust, Targeted Health Outreach Service
- East London Foundation Trust, Child and Adolescent Mental Health Services (CAMHS)
- Kent Community Health Foundation Trust
- Hackney Education, Visual Impairment Teaching Team, Integrated SEND Services, SEND Local Offer and Family Coaching Team
- Baden Powell Primary School
- Comet Nursery School & Children's Centre
- Old Hill Children's Centre Early Help Family Support

## Demographic distribution of CYP with SEND - Parents' survey

**Figure 21: Age group of CYP in City and Hackney with SEND whose parents from responded to the survey (n=89)**



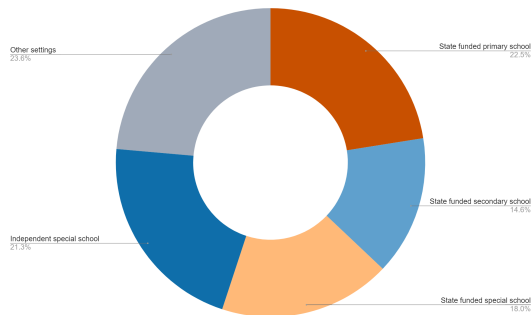
**Figure 22: Age group of CYP with SEND in the Charedi community whose parents responded to the survey (n=60)**



## Type of school - Parents' Survey

The figure below reflects the breadth of educational settings attended by CYP with SEND, with mainstream schools both primary and secondary and independent schools forming the majority of the responses.

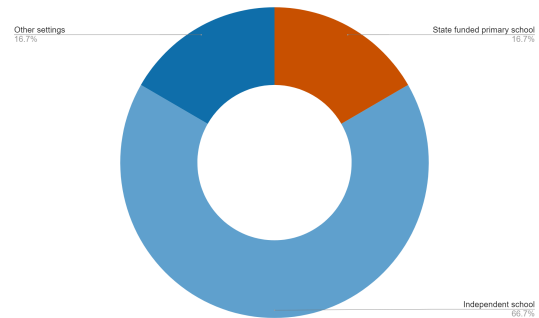
**Figure 23: Type of schools attended by CYP with SEND in City and Hackney whose parents responded to the survey (n=89)**



Note: Other settings grouped categories where the numbers were less than eight. These included independent school, nursery, college; not in school or employment, virtual school, residential setting, waking hour curriculum, state funded school moving to a special school in September 2024, hospital education, university,

in training for supported internship; state funded special school waiting an alternative provision.

**Figure 24: Type of schools attended by CYP with SEND from the Charedi community in Hackney whose parents responded to the survey (n=60)**



Note: Other settings grouped categories where the numbers were less than eight. These included state-funded secondary school, independent special school and nursery.

The Charedi parents survey showed that the majority of the CYP with SEND studied in independent schools, 25% were in mainstream primary and secondary schools (combined), whereas 5% of CYP were in independent special schools.

## Analysis and dissemination of findings

Thematic analysis was used to identify themes within the data. We compared and contrasted responses from participants from different age groups and communities (looking at what different participants said on the same issue). The following steps will be followed in the process:

- Familiarise the data gathered from interviews and focus groups
- Search for patterns or themes in the codes across the different focus groups and Interviews
- Review themes
- Define and name themes
- Include main findings in this report

Although the focus was to capture qualitative insights on the health and wellbeing of CYP with SEND, the responses we received from participants intertwined with other needs. This highlights that social determinants have a strong impact on the health and wellbeing of CYP with SEND.

The communication loop will be completed by sharing key findings and recommendations of this needs assessment with parents, carers, young people and providers who participated in the engagement.

## Data Collection Tools

Different data collection tools were used to gather qualitative insights from different stakeholders including survey questionnaires, focus group questions and one to one interview guide.

The process of developing the questions was based on the principles of co-production, involving members of the CYP SEND Needs Assessment Steering Group, Parent Carer Forums in Hackney and the City of London and some VCSE organisations that work with CYP with SEND. The school head teacher and class teachers were involved with developing focus group questions. We also researched best practices while engaging with young people with SEND and used communication cards and interactive methods while conducting the focus groups. Stakeholders who took part in the focus groups and one to one interviews were offered a gift voucher to reimburse them for their time. Interpretation was offered to parents where requested.

### 1. Focus group questions for CYP with SEND

#### Physical/mental health

1. What do you think being healthy means?
  - If no mention of mental health: Do you think feeling happy and having no worries can also mean someone's health? Any other prompts on mental wellbeing if it doesn't come up in the discussion.
2. What can people do to stay healthy?
  - Do you think there are things that can worsen someone's health? What will they be?
3. How would you know if your health started to get worse?
  - How would your behaviour/mood change if your health became bad compared to when you had good health?
4. How healthy are you right now? What would make you healthier?
5. How do you feel right now? What would make you feel better? (referring to mental wellbeing)
6. Who helps you with your health and feelings? Do you have someone to talk to that you can trust? What do they do to help you?
7. Have you seen anyone (doctor/health professional) to help you with your health and staying well in the last six months? Yes/No
8. If yes, please could you share how you felt after seeing them? (Further probing questions: Were they polite? Did they make you feel comfortable? Did you feel that they listened to you? Did they go through your concerns about your health and wellbeing? Did they arrange for treatment to help with your concerns?)
9. What help would you like with your health and feelings from now on?

### 2. Parent Carer Survey questionnaire

1. How is the health and wellbeing of your child or young person that you care for, right now (on a scale of 1-10, with 1 being worse and 10 being very good)? Please think about mental and physical health and wellbeing.

2. Please give a short explanation for the rating you have given above.
3. How would you know if their health or wellbeing became worse?
4. Please could you describe the health and wellbeing needs of your child or young person that you care for?
5. Who helps with your child or young person that you care for, with their health and wellbeing? What do they do to help?
6. Do you think the child or young person that you care for has someone trusted that they can talk to about their health and wellbeing? If so, who?
7. Do you feel that your child or young person's health and wellbeing needs were diagnosed at the right time?
8. If yes, how do you know?
9. What support do you think would be useful to the child or young person that you care for, to improve their health and wellbeing moving forwards?
10. How old is your child/young person?
11. Which type of school does your child/young person attend?

### **3. Provider Survey questionnaire**

1. Please could you share which organisation you work for and what is your role?
2. What do you think are the key health and mental wellbeing needs of children and young people with SEND?
3. What support does your organisation/team offer to children and young people with SEND with regards to their health and wellbeing?
4. How are children and young people with SEND encouraged to access the support that you offer?
5. Is there a formal referral process? Which professionals are involved in this referral process?
6. Do you feel there is information, advice and services available to children and young people with SEND with regards to their health and wellbeing before they are diagnosed?
7. If yes to the previous question, please could you share any examples?
8. Are timescales within referral pathways into your service stipulated including a specified time within which assessment, diagnosis and treatment need to be provided?
9. If yes, please could you share what are the referral timescales for your service?
10. If yes, Is assessment and diagnosis done within the timescales within those pathways?
11. If not, what are the barriers? Please could you provide suggestions for streamlining any delay in assessment, diagnosis and treatment.
12. Do you feel that there are any specific gaps in the support that is being offered to children and young people with SEND in Hackney and City with regards to their health and wellbeing? If so, what do you think are the gaps and what would be needed to help fill these gaps?

## **Appendix 3: Disabled Children's Service**

Hackney has a Disabled Children's Service (DCS) that provides support for disabled CYP aged 0 to 18 years-old and their families. As of May 2024, 451 CYP were open to the service. (44) Hackney DCS is responsible for provision of short breaks, care packages and support with preparation for adulthood.

Care packages consist of social activities, personal domiciliary care and/or overnight respite support. They are reviewed annually to assess the level of need of the CYP and their families and whether any changes are required to the package. Once the review has been completed the CYP is allocated to a virtual worker. Health officers regularly attend the care package panel and DCS works with CAMHS to show how mental health needs of CYP that are linked to their disability are met. DCS also works with colleagues from a number of hospitals across the City and Hackney partnership to ensure that information is shared appropriately and any concerns can be raised and addressed in a timely way.

The City doesn't have a separate DCS. However, there is a children with disabilities lead in the Children's Social Care and Early Help Team, and they provide the same service provision previously mentioned.

## Appendix 4: Visual Impairment Service

The **Visual Impairment Service** is part of the wider Inclusion and Specialist Support Team in Hackney Education's Integrated SEND service. It is not a health service. This specialist sensory team supports CYP with Visual Impairment or Multi-Sensory Impairment/Deafblindness in home settings, schools and colleges in Hackney. They offer advice and support to families and CYP from diagnosis and beyond by monitoring and supporting CYP's progress throughout all stages of education from 0 to 19 years of age.

The CYP are usually referred to the service in their early years by health professionals, and have different levels of needs. These may vary from CYP with mild visual impairment who have an annual visit to check their impairment is not a barrier to their learning; to a CYP who is blind and requires weekly intensive support to learn how to understand and interact with the world and read Braille, for example.

The Visual Impairment Service has an open referral system. The specialists provide support for CYP to be included in health services and meet their health needs in many ways. This includes giving advice to health professionals, providing support for clinic appointments with families, attending joint home visits with Speech and Language Therapists, Occupational Therapists and Physiotherapists, and attending 'Children in Need' meetings. These activities support CYP to be included in health services and meet their health needs but no data of the health needs are recorded.

As of 28 November 2023, 167 CYP were being supported by the Visual Impairment Service, with 33 of them (19%) also registered with the Deaf and Partial Hearing Service due to Multi-Sensory Impairment.

## Appendix 5: Deaf and Partially Hearing Service

The **Deaf and Partially Hearing Service** is also part of the wider Inclusion and Specialist Support Team and a part of Hackney's Integrated SEND Service enhanced support for CYP with additional needs. The team provides a range of support for CYP aged 0-25 who are deaf or hard of hearing, aiming to improve their education and life outcomes.

As of 28 November 2023, 347 CYP were identified in the Deaf and Partial Hearing Service. Of these, 33 were also registered in the Visual Impairment Service and the Deaf and Partial Hearing Service due to Multi-Sensory Impairment. The service works closely with Audiology, SaLT and other health professionals at Hackney Ark.

Data collected by individual services is not necessarily linked to or shared with other services. Recently, some data from Education and Social Care were linked but Health data is still not integrated. This prevents us fully understanding the health needs of different cohorts of CYP with SEND.



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