Disabled Children’s Needs Assessment for the London Borough of Hackney and the City of London

July 2017

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The Garden School
Ickburgh School
Side by Side School
Woodberry Down Children’s Centre
Interlink
Children Ahead
Hackney Independent Forum for Parents/Carers of Children with Disabilities (HiP)
In Touch

Further information on these organisations and parent groups can be found in the relevant chapters.

2 Glossary

ASD	Autistic Spectrum Disorder
BMI	Body Mass Index
CAMHS	Child and Adolescent Mental Health Services
CCG	Clinical Commissioning Group
CIN	Child In Need
CRC	Convention on the Rights of the Child
CYP	Children and Young People
DLA	Disability Living Allowance
dmft	decayed, missing and filled teeth
DP	Direct Payments
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
EHC plan/ EHCP	Education, Health and Care Plan
FFT	Family Fund Trust
GHS	General Household Survey
GLA	Greater London Authority
GP	General Practitioner
HiP	Hackney Independent Forum for Parents/Carers of Children with Disabilities
HIV	Human Immunodeficiency Virus
HLT	Hackney Learning Trust
ICD-10	International Classification of Diseases, Tenth Revision
ICIDH-2	International Classification
IUGR	Intrauterine Growth Restriction
JSNA	Joint Strategic Needs Assessment
LA	Local Authority
LAC	Looked After Children/Child
LD	Learning Disability
LEAP	Lifestyle Eat-well Activity Positivity
LG Inform	Local Government Inform
MYE	Mid-Year Estimates
NCMP	National Child Measurement Programme
NHS	National Health Service
NICE	National Institute of Clinical Excellence
NSPCC	National Society for the Prevention of Cruelty to Children
OJ	Orthodox Jewish
ONS	Office for National Statistics
PIP	Person Independence Payments
PMLD	Profound and Multiple Learning Disabilities
SEN	Special Educational Needs
SENCO	Special Educational Needs Coordinator
SEND	Special Educational Needs and Disability
SHLAA	Strategic Housing Land Availability Assessment
SNOMED CT	SNOMED Clinical Terms
TCRU	Thomas Coram Research Unit
THOT	Transition Health Outreach Team

UK	United Kingdom
UN	United Nations
WHO	World Health Organisation

3 Executive Summary

This report presents the findings of the Disabled Children's Needs Assessment which aimed to identify and describe the health and wellbeing needs of disabled children and young people aged 0-25 years old in Hackney and the City of London. The document aims to describe the population of disabled children and young people locally by utilising both local and national qualitative and quantitative data. Qualitative data on the local needs of disabled children and young people was collected via a parent focus group and stakeholder interviews with professionals working in health, social care, education and the voluntary sector.

The term disabled children includes children and young people with a vast range of needs. An important finding of this needs assessment is that diagnosis and classification of disability varies across different organisations. Different coding systems are used in General Practice, mental health services, secondary care, education and social services. Due to this variation, it is difficult to establish exact numbers for the disabled population. There is no database nationally or locally that is able to capture all disabled children and young people. However there are estimated to be 15,266 disabled children and young people aged 0-25 in Hackney and the City of London.

There have been numerous acts of legislation and national guidelines published aiming to support those with disabilities and reduce inequalities. National and local drivers regarding the health and wellbeing needs of disabled children are described within this document. Unfortunately, those with disabilities still face numerous barriers and inequalities in aspects of life including physical and mental health, education and employment.

There are estimated to be 985 people aged under 25 years old known to have Autistic Spectrum Disorder (ASD) locally. It is likely that there is a significant under diagnosis of ASD as City and Hackney CCG data record show that there are 18% fewer children and young people with ASD than expected. It is important to identify those with ASD as research suggests that those with the condition have a life expectancy that is 16 years shorter than their peers (without ASD). [1] They are also likely to need long-term support with housing and basic care needs. Only 16% of adults with ASD in full-time paid employment. [2]

Children with a disability are more likely to be obese than their peers without a disability. The cause of this is multifactorial as obesity is linked to developing type 2 diabetes, mobility problems and cardiovascular disease. The National Child Measurement Programme shows that Hackney has higher rates of overweight and obese children than the London and national average. Ensuring a 'whole family' approach to weight management is essential to ensure prevention of obesity and it is vital that appropriate weight management services are in place for those that need them.

Disabled children have poor oral health which manifests as toothache, difficulty with eating and speech. An evidence based fluoride varnish programme has been commissioned for all Hackney and City primary schools (including Charedi independent schools) to reduce dental decay. A local pilot study has established that rates of dental decay in Charedi school children (58.4%) were over double those of the Hackney average (27%).In our special schools, we have commissioned supervised tooth brushing programme as basic oral hygiene is imperative to reducing decay.

Rates of asthma in disabled children and young people (417 per 10,000 males and 319 per 10,000 females) were less than half the national average. As the Aphekom study suggests that 15-30% of new cases of asthma in European children are secondary to air pollution, and London has higher than recommended levels of air pollution, this is unexpected and under diagnosis of asthma in this group of children needs further investigation. [3]

Hackney has a higher percentage of children with Special Educational Needs and Disabilities (16.8%) than the London and England averages (14.5% and 14$% respectively). Those with a disability are over twice as likely to have no formal qualifications as adults. Nationally both absence and exclusion rates are higher in pupils with a statement of Special Educational Needs and Disabilities (SEND) than those without. Of note, fixed period exclusions in pupils with SEND in Hackney (20%) are higher than those without a SEND, and almost double the London average (12.3%). [5]

Transition between child and adult services and preparation for adulthood are an area of focus work both locally and nationally. A key finding of this needs assessment is that there is currently no formalised local transition database to record those individuals on the process from moving from child to adult services.

This needs assessment includes recommendations to improve the health and wellbeing of disabled children and young people and to guide future commissioning. A key recommendation is that key partners from education, health and social care should be involved in a Task and Finish Group to establish the best way of accurately recording data on disabled children and young people locally. Another key recommendation is that social care services should establish a formalised transition database to accurately share relevant information about disabled children and young people.

4 Contents

5 Introduction

The term ‘disabled children’ encompasses a diverse group of children with varying levels of need. Even children with the same condition can require different levels of input and support.

The Department for Education states that currently disabled children face multiple barriers which make it more difficult for them to achieve their potential, and to succeed in education. [6] People with disabilities are over twice as likely to have no formal qualifications compared to those without disabilities. [4] There are also numerous recognised health inequalities faced by those with disabilities. Those with learning disabilities having a significantly reduced life expectancy, 15 years lower than that of the general population. [7] Children with disabilities are twice as likely to be overweight or obese as their non-disabled peers. [8] Disabled children have also been identified as being more vulnerable, with a systemic review estimating disabled children as being over three times more likely to be victims of abuse than their peers. [9] Those with disabilities are more likely to be living in poverty than their non-disabled peers. Young adults are at a greatly increased risk, with 44% of disabled 16 to 24 year olds living in poverty. [10]

Due to these disparities, disabled children have become a focus of government policy, aiming to reduce inequalities in health and wellbeing between them and their peers without disability. Specific government policies are discussed later in this document

5.1 Defining disability

For the purpose of this scope we will use the definition of disability outlined in the Equality Act 2010:

> *‘A physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal day-to-day activities.*[1]’ [11]

Due to this definition being broad and somewhat subjective classification systems are often used, these are described in the following section.

5.2 Classification of disability

5.2.1 International

ICD-10 and ICIDH-2

The World Health Organisation (WHO) has published two complementary systems to classify conditions and disabilities. The ICD-10 and ICIDH-2 classification systems are designed to be used together The International Classification of Diseases, Tenth Revision (ICD-10), categorises diagnoses into bodily systems (circulation, breathing etc.) and also contains sections on congenital conditions (occurring at or before birth). [12]

The International Classification of Functioning, Disability and Health (ICIDH-2) allows categorisation of the functions which are affected, the body structures involved, activities that may be impaired and whether there are environmental factors which may act as barriers to functioning. [13] These barriers include wider determinants of health such as

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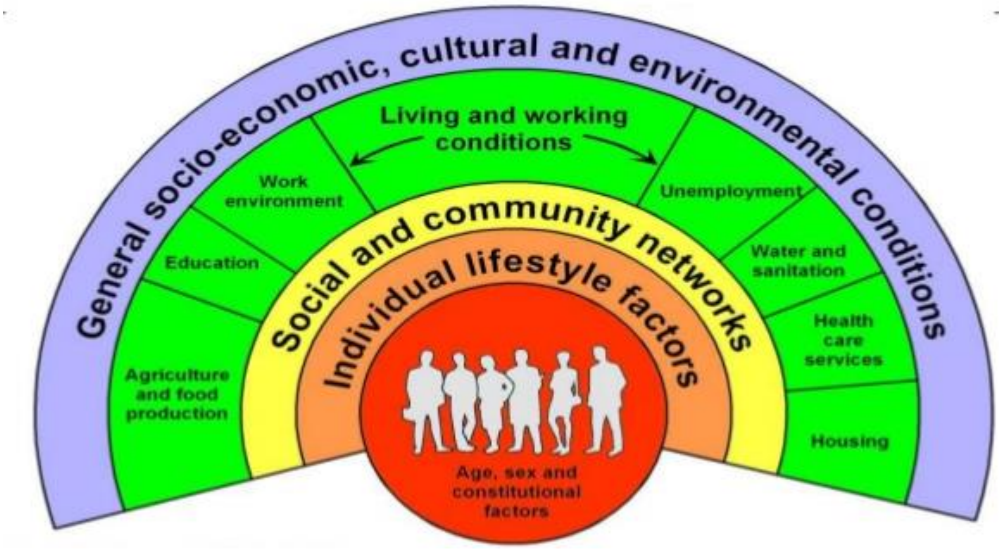
[1] The term ‘substantial’ in this context means more than minor, and ‘long-term’ means 12 months or more.

housing and health care services etc. described by Dahlgren and Whitehead (see Figure 1 below). [14]

Figure 1: The Dahlgren-Whitehead rainbow. The main determinants of health.



Source: The Dahlgren-Whitehead rainbow. Economic and Social Research Council. 2016. [14]

By using a combination of ICD-10 and ICIDH-2 a diagnosis and level of functioning can be outlined. WHO classification systems are used globally and therefore can be used to provide comparable data across populations both nationally and internationally. Within Hackney and the City, ICD-10 codes are not universally used, however are most likely to be utilised within the National Health Service (NHS in secondary care in hospital, particularly on inpatient discharge summaries or outpatient clinic letters.

DSM-5

Another international classification system that is used in the United Kingdom is the DSM-5, the Diagnostic and Statistical Manual of Mental Disorders. It was published by the American Psychiatry Association in 2013. [15] It includes neurodevelopmental disorders such as Autistic Spectrum Disorder, anxiety disorders, depression and other mental health problems. It is mainly utilised in mental health within secondary care, e.g. providing a diagnosis on a clinic letter or discharge summary from an inpatient stay.

5.2.2 United Kingdom

Subdivision and classification of disability nationally varies by institution. Being termed as having a disability, and the specific disability you are diagnosed with is of importance nationally, locally, and for the individual and their family. Having a classification system for recording disability allows organisations to accurately plan service provision and plan funding accordingly. For the individual and their family, by being termed as having a disability, they may be eligible for statutory benefits (such as the Disability Living Allowance) and access charity aid and voluntary services. Some statutory benefits are condition or functionality specific. For example, if a child is assessed as requiring a higher level assistance with movement, the mobility component of their disability living allowance more than doubles. However, some may consider being diagnosed as having a disability as stigmatising, potentially leading to discrimination, bullying and isolation.

School Special Educational Needs and Disability Data

Special educational needs and disability (SEND) data recording within schools categorises children according to their ‘primary type of need’, such as moderate learning difficulty, or physical disability. A pupil’s primary type of need is the need which most significantly affects their education. The only named specific disability on the list of SEND primary needs is autistic spectrum disorder, however this covers a spectrum of disability and functioning rather than being one homogenous population. The broad areas of need outlined in the SEND Code of Practice [16] are:

- Communication and interaction
- Cognition and learning
- Social, emotional and mental health difficulties
- Sensory and/or physical needs

Children can be classified as having one need or multiple needs and the SEND Code of Practice recommends a detailed assessment of all needs rather than solely the primary need should be conducted.

Office of National Statistics

The UK Office of National Statistics (ONS) gathers data from the Family Resources Survey on the prevalence of national disability, including childhood disability. [17] It sub-divides impairments into functions effected, for example, vision, hearing, mobility and dexterity.

Read Codes

Read Codes are a thesaurus of clinical terms that have been use in the NHS since 1985. [18] It includes symptoms, examination findings and diagnoses. In Hackney and the City of London it is currently utilised in primary care within General Practice (GP) surgeries. However, over the next few years all GPs in England will be moving to using SNOMED CT.

SNOMED Clinical Terms

SNOMED Clinical Terms (SNOMED CT) is a system initially developed in Denmark by the International Health Terminology Standards Development Organisation. It provides a list of terminology encompassing symptoms, clinical findings, diagnoses, organisms, substances and pharmaceuticals. [19] Although SNOMED CT is used in 50 countries worldwide, nationally a UK clinical Edition is used. In Hackney it is utilised currently in Accident and Emergency summaries and in inpatient hospital discharge summaries in secondary care. The National Information Board in the document ‘personalised Health and Care 2020: A Framework for Action’ recommended that all care settings in England should move to utilising SNOMED CT. It recommended that all primary care settings should be using SNOMED CT by April 2018. Secondary care, acute care, mental health, community systems, dentistry and other systems should utilise SNOMED CT by April 2020. [20]

5.3 Variation in classification systems

The varying classification methods are summarised below in Figure 2. This variation in classification system means that it may be difficult to compare data between different organisations. For example, assessing the number of children with Down’s syndrome in education may be difficult as healthcare records use ICD-10 diagnoses, whereas schools would code the child according to their primary need, such as learning disability or visual impairment, rather than their condition.

Figure 2: Table comparing classification systems for disability.

International
ICD-10 and ICIDH-2
Both published by the World Health Organisation. ICD-10 and ICIDH-2 are designed to be used in conjunction. ICD-10 classifies and describes diagnoses. ICIDH-2 describes function and barriers to the individual. Used in secondary care health services.
DSM-5
Published by the American Psychiatry Association. Classifies and describes mental health problems. Used in mental health services.
United Kingdom
School Special Educational Needs and Disabilities
Categorises children and young people by primary type of need rather than diagnosis. Used by schools when reporting to the Department for Education for the school census.
Office of National Statistics
Divides impairments by the function affected. Used by the Office of National Statistics in the Family Resources Study for self-reporting.
Read Codes
Thesaurus of clinical terms encompassing terms used across medical notes including diagnoses, symptoms, examination findings. Used in General Practice.
SNOMED CT
A terminology system used to code medical notes. Used in secondary care currently. Planned to be utilised across all healthcare services in England by 2020.

Source: As above

One rationale to having several systems is that different organisations require different data for monitoring and service planning. For example specific diagnoses are important in healthcare as this will influence treatment required and can be used to measure the numbers with a particular condition locally and nationally to calculate incidence and prevalence. Whereas in schools, specific diagnoses are less relevant. For example, the majority of those with hearing impairments are likely to require similar adaptations and considerations regarding education regardless of the specific condition causing the hearing impairment.

5.4 Causes of childhood disability

The causes of childhood disability are vast, and often multifactorial. A full literature review of the many causes of disability is not within the scope of this assessment but a brief overview of common causes is outlined below:

5.5.1 Antenatal

- Maternal age- increased age associated with increased risk of Down syndrome
- Malnutrition/Nutritional deficiencies - e.g. folate
- Iatrogenic/Teratogenic substances - e.g. medication such as warfarin
- Maternal alcohol or substance misuse
- Smoking
- Genetic causes e.g. Down’s syndrome or Turner’s syndrome
- Maternal infection during pregnancy e.g. rubella
- Maternal trauma
- Intrauterine growth restriction (IUGR) - babies with IUGR are smaller than would be expected and this may be due to maternal diabetes, hypertension, smoking or other causes. IUGR babies are more prone to neurodevelopmental problems, breathing problems and other complications.

5.5.2 Around/during childbirth

- Hypoxic brain injury during birth
- Iatrogenic/Trauma
- Infection- vertical transmission from mother to baby of infections such as cytomegalovirus, chickenpox and gonorrhoea.
- Prematurity- premature babies (defined by WHO as those born before 37 weeks gestation) are more at risk of complications such as hearing impairment, visual impairment, breathing problems and neurodevelopmental problems.
- Macrosomia- babies which are larger in size when they are born are at risk of complications such as shoulder dystocia when delivered vaginally which can lead to nerve palsy.

5.5.3 Postnatal

- Trauma/injury
- Infection
- Malnutrition/Nutritional Deficiency

- Genetic –some conditions have a later age of onset of symptoms such as Duchenne muscular dystrophy.
- Developmental- these are often detected in early childhood.
- Toxins/Iatrogenic e.g. medication (ototoxic drugs)

5.5 National context, policy and legislation discussed

The existence of discrimination against those with disabilities has been documented for many years. Implicit Association Tests by Harvard University looking at unconscious instantaneous prejudices found that of over 12,000 people 72% showed evidence of an implicit preference for people without disabilities over disabled people with over a quarter of people showing a strong preference for those without disabilities. [21]

A review by Scope of discrimination against those with disabilities in 2006 found numerous examples ongoing reduction in opportunities. This included:

- Only 10% of childminders offering services for disabled children.
- Disabled men working over 30 hours a week earnt £1.10 less per hour than their non-disabled peers, with disabled women earning 50p less per hour.
- Nearly a quarter of disabled people do not have the adaptations to their housing they require.
- Only 40% of households with a disabled person have access to a private car compared to 63% of the general population.
- Over two-thirds of young people with disabilities felt they could not access the leisure activities their friends did.
- 81% of websites did not satisfy the most basic level of Web Accessibility Initiative criteria. [21]

There have been attempts to address these areas through policy change and legislation. Key areas of policy and legislation regarding disabled children and young people selected to be discussed are those that aim to ensure they receive equal opportunities to their peers without disabilities.

An over-riding message is that services should make reasonable changes to ensure disabled children have access to appropriate healthcare, education, childcare and housing. The importance of, and processes to ensure, safeguarding of this vulnerable population is another repeated theme. The approach of document selection is discussed in the methodology section (see section 22).

Relevant documents discussed are:

Legislation
Education Act 1981
The Children Act 1989
Disability Discrimination Act 1995
The Community Care (Direct Payments) Act 1996
Housing Act 1996 (and 2004 amendments)
Special Educational Needs and Disability Act 2001
Equality Act 2010
Children and Families Act 2014
Government Policy
Every Child Matters (2003), Department for Education
You’re Welcome- Quality Criteria for Young People Friendly Health Services (2011), Department of Health
Support and Aspiration: A new approach to SEN and disability (2011), Department for Education
Transition to the new 0 to 25 special education needs system by 2018 (2015), Department for Education
Publications from other organisations
We have the right to be safe’: Protecting disabled children from abuse (2014), NSPCC
Priced out: ending the financial penalty of disability by 2020 (2014), SCOPE
Transforming mental health: A plan for action for London (2014), The King’s Fund
People in control of their own health and care (2014), The King’s Fund Driving down the extra costs disabled people face (2015), Extra Costs Commission
Do Siblings Matter Too? (2015) University of Portsmouth and Family Fun
Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (2015) NICE guideline
Transition from children’s to adults’ services for young people using health or social care services (2016) NICE guideline
Disability and Poverty (2016), New Policy Institute (commissioned by the Joseph Rowntree Foundation)

Disability Matters in Britain 2016: Enablers and challenges to inclusion for disabled children, young people and their families (2016) The Royal College of Paediatrics and Child Health

5.6 Services available for disabled children and young people

Research into childhood disability and its causes have led to advances in both reduction of disability (such as recommending folic acid supplements for those planning to conceive to reduce the risk of spina bifida) and early diagnosis (via antenatal scans, parental blood tests etc.). There are also numerous services and programmes in place to target identification of disability at an early age. Additional services aim at improving the wellbeing of disabled children. Services are commissioned both nationally and locally and area outlined below.

5.6.1 Nationally commissioned services

- Healthy Child Programme- This programme offers every family access to services to help improve their health and wellbeing. This includes screening tests, immunisations, developmental reviews and information and guidance to support parents.
- Antenatal screening
    - *Foetal Anomaly Screening Programme*- using ultrasound scans abnormalities in body organ development may be identified. Using a combination of ultrasound and blood tests genetic conditions (Down's, Edwards' and Patau's syndromes) may be identified.
    - *Infectious Diseases in Pregnancy Screening*- Mothers are screened for HIV, hepatitis B and syphilis to try and reduce transmission between mother and baby.
    - *Sickle Cell and Thalassaemia Screening*- Tests to identify whether mothers are carriers of genes for sickle cell and thalassaemia (conditions which affect blood cells). If mothers are positive, fathers are then tested to assess the probability of the child having the condition.
- Postnatal screening
    - *Newborn and Infant Physical Examination-* This is conducted shortly after birth in the hospital and repeated 6-8 weeks after birth usually by the GP. The baby has a general examination including listening to the heart to check for murmurs, checking the babies eyes for problems such as cataracts and the hips to assess for Developmental Dysplasia of the Hips.
    - *Newborn Blood Spot Test*- Blood from the baby's heel is used to test for sickle cell disease, cystic fibrosis, congenital hypothyroidism and inherited metabolic diseases[2].
    - *Newborn hearing screen-* This aims to identify hearing impairments as early as possible and is usually conducted on the postnatal ward before the baby is discharged from hospital. It should be conducted before the child is 5 weeks old.

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[2] Six inherited diseases are tested for. These are: phenylketonuria (PKU), medium-chain acyl-CoA dehydrogenase deficiency (MCADD), maple syrup urine disease (MSUD), isovaleric acidaemia (IVA), glutaric aciduria type 1 (GA1) and homocystinuria (pyridoxine unresponsive, HCU).

    - *Health visitor developmental checks*- Health visitors check whether the child is meeting the expected developmental milestones for their age. In Hackney the universally commissioned checks for all are the antenatal check, the new baby check, the 6-8 week check, the 1 year check and the 2-2½ year check. Hackney also commissions two additional checks at one month and 3-4 months of age for targeted families who may require additional support, such as first time parents for example.
- National Child Measurement Programme (NCMP) - The programme measures the height and weight of children attending state maintained mainstream schools in reception class and year 6 to assess levels of overweight and obese children of primary school age. In 2015 a pilot scheme measuring the height and weight of reception children attending Charedi schools was commenced. The findings of the NCMP and the Charedi pilot are discussed in more detail in Section 11: Obesity.

5.6.2 **Local services as outlined in the Hackney Local Offer [22]**

The Hackney Local Offer website outlines services available for children with special educational needs and disabilities. It covers health, social care, education, voluntary services and community groups and divides them into the following subgroups:

- Childcare Services
  Information on nurseries, playgroups, breakfast and after school clubs as well as other childcare providers such as childminders.
- Education
  An overview of the nurseries, state-maintained and independent mainstream and special schools available in the borough.
- Family Support
  Services that provide parental advice and support. As well as general support this include specific services for LGBT individuals, refugees and asylum seekers and those affected by domestic violence.
- Health and Specialist Services
  Included within this group are specialist disability services, those related to alcohol and substance misuse, mental health and sexual health.
- Things to Do
  This section outlines leisure and recreation activities available such as music and dance classes, sports groups and adventure parks.
- Money, Transport, Work and Housing
  Services which support those with disabilities in accessing transport, appropriate housing and financial support are within this section. Employment and volunteering services in the transition to adulthood are also included.
- Children’s Centres
  These provide early years support and childcare places, family and parental outreach, and are often a base for other child and family services such as breastfeeding support etc.
- Young Hackney
  This service is for all young people aged 6-19, and up to 25 years if the young person has a special education need or disability. Young Hackney is the Council’s early help, prevention and diversion service providing universal activities as well as targeted support to priority group and individuals.

6 National and Local Context

The rights of those with disabilities and the services that should be statutorily available to them are influenced nationally by Acts of Parliament and government policy. Services recommended for those with disabilities are influenced both by government, the healthcare sector (such as the National Institute of Clinical Excellence) and reports from other organisations.

The Equality Act 2010 [23] defines a person as having a disability if they have:

> *'a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities'*[3]

Establishing the exact number of children and young people who are disabled is difficult as no particular method that ensures that every individual is identified. The Government utilises the Family Resources Survey to calculate prevalence of disability in the United Kingdom. It involves self-reporting of physical or mental health conditions and limitations on activity. The percentage of the total population (adults and children) with disabilities has steadily increased, from 18% in 2004/05 to 20% in 2014/15. [24] The percentage of disabled children identified via the survey in 2014-15 was 7%, an increase from 5% in 2004/5.

This increase is likely to be multi-factorial, with possible contributors being improved diagnostic methods, and medical advances extending the life of children and adults who may otherwise not have survived due to their disability and associated complications.

It is important that these increasing numbers of disabled children are identified so that provisions in health and other aspects of wellbeing can be planned to meet their needs. Reviewing legislation and policy relevant to children and young people with disabilities enables local authorities and health services to ensure they meet the statutory recommendations outlined. There are various acts of legislation and policy that aim to meet health and social needs, reduce discrimination and secure the rights of disabled children. This section of the assessment will cover relevant international, national and local documents. The methodology of document selection is outlined in Section 22 in the Methodology and Limitations Chapter.

6.1 International Policy

The United Nations published the Convention on the Rights of the Child (CRC) in 1989. [25] Worldwide, all United Nations members other than the USA, have ratified the convention. The Convention, which was signed by the UK in 1990, includes specific articles addressing the rights of disabled children in particular:

- Article 2 states that 'children should never be discriminated against on the grounds of disability'.
- Article 23 outlines the importance of exercising the independence of disabled children to the greatest extent possible.

The United Nations Convention on the Rights of Persons with Disabilities (2006), Article 7, advises that disabled children should have 'full enjoyment of all human rights and fundamental freedoms on an equal basis with all other children'. [26]

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[3] The term 'substantial' in this context means more than minor, and 'long-term' means 12 months or more.

6.2 National Context

6.2.1 Government Legislation

By signing the above United Nations conventions, the United Kingdom is bound by international law to work to meet these articles. However, the government has established acts of legislation to provide further statutory protection and support to disabled children:

Education Act 1981 [27]

This Act was the first piece of UK legislation to recognise the term ‘Special Educational Needs’. It defined the term as including children with ‘a learning disability, which may be the result of a physical or sensory disability, an emotional or behavioural problem, or developmental delay’.
The Act outlines that wherever possible, children with special educational needs should be educated within mainstream schools.

The Children Act 1989 [28]

Certain aspects of this Act provide additional support for disabled children and their families. Important messages are:

- Every local authority should provide day care for all children in need aged 5 and under not yet attending school. All children with disabilities are classified as children in need.
- Local authorities should provide all disabled children attending school with care outside school hours and during school holidays.
- Short breaks should be provided by local authorities under their power to provide accommodation as part of a range of services to promote the welfare of disabled children.
- Local authorities have a duty to monitor the welfare of children in residential education or hospital provisions and ensure that they are adequately safeguarded.

Disability Discrimination Act 1995 [29]

The Act states that it is unlawful to discriminate against someone in respect of their disabilities with regards to areas such as employment, accessing services, education and transport.
The Equality Act 2010, has now replaced the Disability Discrimination Act.

The Community Care (Direct Payments) Act 2000 amendments [30]

Prior to this act service users had little choice over their care providers and the timing of care provided. The Community Care Act came into force in 1997, allowing local authorities the ability to dispense cash payments to disabled adults. This aimed to allow them independence in deciding on care providers and the manner in which care was delivered. The Act was later amended in 2000, and along with the Carers and Disabled Children Act 2000, extended the cash payments to parents of disabled children, and also to the disabled children themselves if aged 16 or 17.

Special Educational Needs and Disability Act 2001 [31]

This legislation aimed to make further provisions against discrimination by educational institutions. It required schools, colleges and universities to make reasonable provisions to ensure that those with special educational needs and disabilities were provided with the same opportunities as their peers without SEND. It states that an educational institutional is unlawfully discriminating against those with disability or special educational needs if it fails to make reasonable adjustments to accommodate them, or when treating them less favourably.

Housing Act (with 2004 amendments) [32]

The Housing Act states that local authorities must give reasonable preference to individuals who need to move due to medical or welfare reasons. Disabled children are included within this group of individuals. Local authorities are also mandated to have a homelessness strategy and aim to prevent homelessness for families with disabled children by the Homelessness Act (2002).

Children and Families Act 2014 [33]

The Children and Families Act states that

'A local authority in England must exercise its functions with a view to securing that it identifies-

a) All the children and young people in its area who have or may have special educational needs, and
b) All the children and young people in its area who have a disability'

The Act also outlines four key principles that Local Authorities must follow with regards to children and young people with special educational needs and disabilities:

1. Consider the views, wishes and feelings of the child, young person and their parents.
2. Involve the child, young persons and their parents in decisions that affect them.
3. Give the child, young person and their parents the information and support they need to be involved in decision making.
4. Support the child, young person and their parents to achieve the best possible outcomes.

The Act also fully introduced Education and Health Care (EHC) Plans to replace Statements of Educational Needs and Learning Difficulty Assessments. EHC plans are issued by the Local Authority and are required for all children with special educational needs or disabilities whose needs could not be adequately supported with usual school or college input alone.

The EHC plans cover those aged up to 25 unless the young person:

- Goes to university
- Becomes employed
- Informs their local authority they do not want the plan
- Is assessed by the local authority as no longer requiring the EHC plan at review

In addition to providing support towards meeting educational needs EHC plans pertain to health care provision and social care provision that is required. By encompassing these domains the EHC plans should encourage multi-agency communication. Annual reviews should be conducted and the Local Authority may then make changes to the plan if required.

Summary of Legislation

KEY POINTS
- It is unlawful to discriminate against anyone due to their disability. - Local authorities should provide families of disabled children access to Short Breaks. - Local authorities should provide care for disabled children outside school hours and during school holidays. - Local authorities must place disabled children in a priority list with regards to housing. - Educational institutions must make reasonable provisions to ensure that disabled children are have access to the same opportunities to their peers without disabilities. - Local authorities should involve disabled children and young people and their families in decisions that affect them. - All disabled children and young people whose educational needs cannot be supported by usual school input should have an Education and Health Care Plan. - Education and Health Care Plans should outline the educational, health and social care needs of the individual and can be used up to 25 years of age.

6.2.2 Government Policy

In addition to statutory Acts the government also publishes policies. These outline the government's plans and intentions. There are government policies, programmes and publications which particularly relate to disabled children and young people, these are detailed below.

Every Child Matters (2003), Department for Education

This Green Paper outlined policy aiming to ensure that every child received the support they required to:

- Stay safe
- Be healthy
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

The initiative covered every child up to the age of 19, and for those with disabilities up to the age of 24. [34] It was released following Lord Laming's report into the death of Victoria Climbié and aimed to put measures in place to better safeguard children. Another crucial aim was to improve educational achievement.
To achieve these goals the policy proposed:

- Creating Sure Start Children's Centres in deprived areas, combining childcare, health services, family support and employment advice in one location.
- Promoting schools providing breakfast clubs and after-school childcare.
- Creating a Young People's Fund of £200 million to facilitate out of school activities for children.
- Increasing investment in Child and Adolescent Mental Health Services (CAMHS) to increase the capacity by 10% each year for three years.
- Making the creation of multi-agency Local Safeguarding Children Boards a statutory requirement, improving communication and coordination of services between relevant authorities.
- Providing targeted and specialist support for parents whose children require additional support.

This policy document influenced the creation of the Children and Families Act.

National Child Measurement Programme (2006)

The programme was established in 2006 in a bid to help gather population-level data, and utilise local data to plan and deliver obesity services for children attending state-maintained schools. [35] Children in Reception (aged 4-5) and Year 6 (aged 10-11) have their height and weight measured. Only children who are able to stand on the weighing scales unaided should be measured. [36] Those unable to do so are legally exempt and should be excluded from the total number of those eligible for measurement. This is an issue for those children with disabilities who are unable to stand as it has been established that those with limiting illnesses/disabilities are more likely to be obese, particularly if they have a learning disability. [37] Local results are discussed in Section 11: Obesity.

You're Welcome- Quality Criteria for Young People Friendly Health Services (2011), Department of Health

This document was published in 2011 to provide a framework for those creating and commissioning services for children and young people. [38] It outlines a ten point criteria to meet to help ensure services were friendly to young people, those particularly relevant to disability are outlined in
Figure 3.

Figure 3: Quality criteria for young people friendly services relevant to disability

Criteria	Relevance to disability
Accessibility	The service should make reasonable adjustments to improve accessibility in accordance with the Disability Discrimination Act.
Publicity	Material concerning the service should be available in a format easily understood by those with learning disabilities, and in formats appropriate for those with sensory impairment (e.g. large font, Braille).
Confidentiality and Consent	A policy on confidentiality and a clear protocol regarding safeguarding and breeching confidentiality should be in place.
Environment	Staff should consider the physical and cognitive ability of the young people using the service.
Staff training, skills, attitudes and values	Staff should be trained in, and receive relevant appraisal in, supporting young people to make informed decisions.
Joined-up working	Where possible, other relevant services should be co-located within the service.
Young people's involvement in monitoring and evaluation of patient experience	The service should encourage all clients to give their opinion on the service and whether it meets their needs.

Source: You're Welcome – Quality criteria for young people friendly services (2011), Department of Health [38]

Support and Aspiration: A new approach to SEN and disability (2011), Department for Education

To improve awareness introduce transparency of local services available for disabled children and their care-givers, this Green Paper required each local authority to create a local offer. [39] The local offer should include all services available, in an easy to navigate and easy to understand format.

This paper also proposed introducing Education and Health Care Plans to replace previous statutory Statements of Special Educational Needs and Disability Learning Assessments. The goal was to improve inter-service coordination and work with families.

Special educational needs and disability code of practice: 0 to 25 years (2015), Department for Education, Department of Health

This document paid particular attention to the early years from birth to school-age. If at any point from birth a child is identified as having a disability or special educational needs the local authority should be informed so that specialist input and support can be commenced as soon as possible. [40]

Transition to the new 0 to 25 special education needs system by 2018 (2015), Department for Education

This governmental report outlined the government's aim that local authorities transfer all children from the statements of SEN and LDAs to the new EHC plans by April 2018. [41] This departmental advice document advised that no child or young person should lose their previous statement of SEN or LDA and not have it replaced with an EHC plan.

Summary of Government Policy and Reports

KEY POINTS

- Local Safeguarding Children Boards are a statutory requirement.
- Nationally, only children in state-funded mainstream schools are included in the National Child Measurement Programme. Children attending special schools and children unable to stand on the scale unaided are not included in the measurements.
- There is a 10 point 'You're Welcome' framework for those commissioning or designing services for young people to improve accessibility
- Local authorities are obliged to publish a local offer outlining the services available for disabled children and young people in their community.
- Local authorities should be informed of a child having a disability as soon as it is identified.
- All children and young people with a Statement of Special Educational Needs or a Learning Disability Assessment should be transferred to Education and Health Care Plans by April 2018.

6.2.3 Publications and Guidelines from other relevant organisations

Governmental policy and healthcare guidelines are often based on research and data collected by outside organisations such as the National Institute of Clinical Excellence, the King's Fund and charity groups. In recent years there have been several important pieces of such literature.

'We have a right to be safe': Protecting disabled children from abuse (2014), National Society for the Prevention of Cruelty to Children

This report explored why recognising and responding to the abuse of disabled children can be delayed or missed altogether. Unfortunately, systematic reviews have shown that up to a quarter of disabled children will be the victim of some form of abuse. [42] The NSPCC report explained that signs of abuse, such as change in mood or behaviour, are at times attributed to be secondary to the child's disability rather than being further investigated. [43] This was reiterated in the 2015 NICE guideline 'Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges'. [44] The NICE guideline reminds practitioners that chid maltreatment is common and to be aware that abuse can cause or contribute to behavioural change or difficult behaviour.

Disabled children have been found to lack information regarding abuse and child protection, particularly those with special educational needs, thereby having a lower ability to keep safe with regards to inappropriate touch and domestic abuse. Suggestions made to safeguard children further include the need for sex and relationship education, to raise children's awareness of abuse and aim to encourage them to seek help.

Priced out: Ending the financial penalty of disability by 2020 (2014), Scope

This report explains that those with disabilities spend, on average, £550 each month on expenses related to their disability. [45] However, the financial aid they receive via benefits may not cover these costs in their entirety. This contributes to disabled people being more likely to be in debt, being twice as likely as those without disabilities to have unsecured debts over half their household income. Those with disabilities are therefore less likely to build savings, on average having over one hundred thousand pounds fewer in savings and assets than those without disabilities. Scope recommended that policy-making should be cross-departmental to identify the root causes of these extra costs and aim to reduce them.

Transforming mental health: A plan of action for London (2014), The King's Fund

This document outlined the unmet need in mental health. It estimated that only a quarter of those with depression and anxiety were actually receiving treatment. [46] Children are a particular group which have a limited choice of therapy and poor rates of access. To improve this, it is recommended that service users, carers and clinicians should all be consulted when services are commissioned.

People in control of their own health and care (2014), The King's Fund

This publication examined methods to increase independence and improve quality of life. [47] One such method is the use of personal budgets in setting care plans. Personal care budgets have been found to be the most cost-effective in young people with disabilities.

[48]However, to be effective these care plans need to be reviewed regularly, to ensure they are meeting the individual's needs. It recommends that public health projects should pay particular focus to children and adolescents, building resilience and social skills programmes. Also it is vital that data collection regarding mental health is re-assessed. Organisations often use different measures for similar outcomes which makes comparison of data difficult. Using the same measures will allow direct efficacy and uptake of services to be judged.

Do Siblings Matter Too? (2015), University of Portsmouth and Family Fund

This report was based on data gained from over 2000 assessments by the Family Fund. [49] This established key findings:

- Siblings of disabled children are not identified or monitored by local authorities and schools.
- Siblings' needs are often not considered or are overlooked.
- Siblings of disabled children may benefit from services such as CAMHS, however few access or receive support from these services.

One of the recommended actions was to commence a register of siblings of disabled children to ensure they receive support and that they should be classified as children in need along with their disabled sibling. It also recommended that local authorities should include services for siblings within their Local Offer to signpost families to support available.

Transition from children's to adults' services for young people using health or social care services (2016) National Institute of Clinical Excellence

Transition is defined by the National Institute of Clinical Excellence (NICE) as a

> "purposeful and planned process of supporting young people to move from children's to adults' services". [50]

Unfortunately the transition from children's to adults' services for disabled children has been described a 'cliff edge' with no clear route to a fulfilling adult life. To combat this NICE published a guideline aiming to improve and standardise transition services. It recommends that practitioners involved in the child's care should begin planning for adulthood from age 13-14 at the latest, and should be held annually or more frequently if required. The transition meetings should involve all those involved in the child's care from multiple agencies and involve the child and their family also. To ensure that services are coordinated each child should have a 'named worker' to oversee their transition to adulthood and help them navigate services. Transition should cover:

- Education and employment
- Community inclusion
- Health and wellbeing, including emotional health
- Independent living and housing options

The young person's named worker should remain involved in their transition for at least 6 months following moving to adult services and should hand over to a named worker within the adults' team.

Disability and Poverty (2016) New Policy Institute (commissioned by the Joseph Rowntree Foundation)

This report emphasised the importance of tackling poverty amongst disabled people, as disabled people make up 28% of all those in poverty. [10] Young adults, those aged 16 to

24, are particularly at risk with 44% living in poverty. The report outlined various factors that contribute to poverty, one that concerns children and young people with disabilities in particular is level of qualification. Over a fifth of those with disabilities have no formal qualifications, this is over double the proportion of those without disabilities. By aiming to reduce this ‘skills gap’ we could possibly improve employment opportunities for those with disabilities.

The report also discussed the potential impact of Universal Credit on those with disability, of significance it reduced the disabled child addition to half its current size. This reduction will likely exacerbate the levels of poverty for families caring for disabled children. Various charities have raised concerns regarding this.

Disability Matters in Britain 2016: Enablers and challenges to inclusion for disabled children, young people and their families (2016) The Royal College of Paediatrics and Child Health

This report collates the views of 10 disabled young people, 123 parents who care for a disabled child or adult and 128 professionals or volunteers who work to support disabled children and young people. [51] The report describes the different factors that are both enablers and barriers to inclusion for those with disabilities. Factors that were identified as enabling inclusivity are outlined in Figure 4 below.

Figure 4: Factors which enable inclusion for disabled children, young people and their families

Enablers to inclusion
Professions who value diversity and see the person, not just their disability.
Those who communicate well, keeping everyone informed.
Empowering disabled people and their families to be resilient and advocate for themselves
Ensuring accessible lifts, doors, changing places and toilets and play and leisure facilities are in place.
High quality specialist services which involve disabled people in their design.
Arrangements for appropriate risk assessments for health and safety, manual handing and personal care.
Easily accessible, timely information and support.

Source: Disability Matters in Britain 2016 (2016) [51]

Findings from publications and guidelines

KEY POINTS

- Up to a quarter of disabled children will suffer abuse of some kind.
- It is estimated that only a quarter of those with depression and anxiety are receiving treatment.
- Transition services should commence at age 14 and reviews should be held at least annually
- 44% of disabled young people aged 16 to 25 live in poverty.
- A fifth of those with disabilities have no qualifications, double the number of those without disabilities.

6.3 Local Context and Stakeholders

Although there are national programmes and policies in place to care for disabled children and young people, local services can differ substantially. The needs of the local population are assessed in each borough and services are commissioned based on the information gleaned.

6.3.1 City and Hackney Clinical Commissioning Group

A Clinical Commissioning Group (CCG) is an NHS organisation which is overseen by NHS England. It is run by GPs and is responsible for commissioning of services for local patients. The City and Hackney CCG consists of 9 programme boards[4] where commissioning of services are discussed. The needs of disabled children and facilitating services for disabled children is under the remit of the Children’s Board. Services are commissioned to local organisations such as the Homerton Hospital and the GP Confederation.

In April 2016 the CCG identified obesity and mental health as being particular priorities. [52]

6.3.2 City and Hackney Health and Wellbeing Board

The Health and Wellbeing Board is a statutory committee of the Council. It includes members from the NHS Clinical Commissioning Group, Hackney Council, Healthwatch (a local health and care watchdog) and the voluntary and community sector. The aim of the board is to improve the health and wellbeing of the local population by ensuring commissioning plans reflect the findings of local needs assessments and the Joint Strategic Needs Assessment (JSNA). [53]

The JSNA for Hackney and City of London was most recently updated in January 2014, [54] prior to this the most recent assessment was the Health and Wellbeing Profile 2011/12. This outlined the population of Hackney, the society and environment in which they life and their lifestyle and behaviour.

Children and young people have been identified as a particular focus, and the most common disabilities in the local population were learning difficulties, language difficulties and emotional and behavioural problems. By being aware of the numbers of children in the boroughs with particular disabilities, service provision and engagement with services can be better assessed and planned for.

An important subgroup of children within the population identified are the Orthodox Jewish (Charedi) community, whom are often educated outside state-maintained schools, therefore are often not identified via programmes such as the National Child Measurement Programme.

6.3.3 City and Hackney GP Confederation

The GP confederation includes all GP practices within City of London and Hackney. Each practice contributes financially and the money is invested in improving and creating services for local patients. The Confederation influences commissioning by bidding to provide services funded by the CCG.

6.3.4 Parent/Carer groups

There are organisations such as Hackney Independent Forum for Parents/Carers of Children with Disabilities (HiP) [55], the Children’s Disability Forum [56], and the Charedi

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[4] The Programme Boards are: Children, Integrated Care, Long Term Conditions, Maternity, Mental Health, Planned Care, Prescribing, Primary Care Quality, and Urgent Care.

parent support group In Touch. As well as providing support and advice to parents, parent representatives attend strategic and commissioning meetings, helping to advocate for parents and service users.

6.3.5 Interlink

Interlink is an umbrella organisation for charities and voluntary organisations that provide services for the Charedi community. They also work with the public sector to increase understanding of the community. Members of Interlink and its member organisations attend strategic and commissioning meeting to ensure that the specific needs of the community are considered.

6.3.6 Database which influence local commissioning

Hackney: The Key

This is a voluntary register for disabled children and young people. The aim of the register was for it to be used to help plan local services and ensure that the needs of all disabled children and young people are responded to. [57] Parents, carers and young people voluntarily sign up to be included on the register. Information gathered from those registered can then to influence local commissioning and aim to reduce unmet needs of disabled children within Hackney.

6.3.7 Key Points - Local Context

KEY POINTS

- Children and young people are a priority area for Hackney and the City, as outlined in the Joint Strategic Needs Assessment.
- The health and wellbeing boards and the CCG are involved in commissioning services for disabled CYP.
- There is a voluntary register for disabled children and young people in Hackney.
- Parent representatives from parent groups are invited to attend strategic and commissioning meets to help provide user feedback to influence commissioning.

7 Population

The demographics of Hackney and the City of London differ considerably. It is important to recognise these variances when assessing local needs and planning service provision.

Throughout this needs assessment, Hackney will be compared to its statistical peers. Hackney's statistical peers are local authorities with a similar demographic make up to Hackney, used for the purpose of comparisons. For data on children and young people, Hackney's statistical peers are Brent, Enfield, Greenwich, Hammersmith and Fulham, Haringey, Islington, Lambeth, Lewisham, Southwark, and Waltham Forest as outlined on the Local Authority Interactive Tool published by the Department for Education. Please note that these differ from the statistical peers used to compare adult or total population data.

The City of London has a much smaller population than Hackney, estimated to be 8500 currently, with a smaller proportion than that of the Hackney population of children and young people. Where relevant and possible in this Needs Assessment data will be divided into Hackney and the City of London. Where figures are extremely low and may lead to confidentiality issues the data for Hackney and the City of London will be combined or City of London data will be withheld and this will be stated when it occurs. For certain data (such as City and Hackney CCG) data for both Hackney and the City of London are routinely combined.

7.1 Hackney

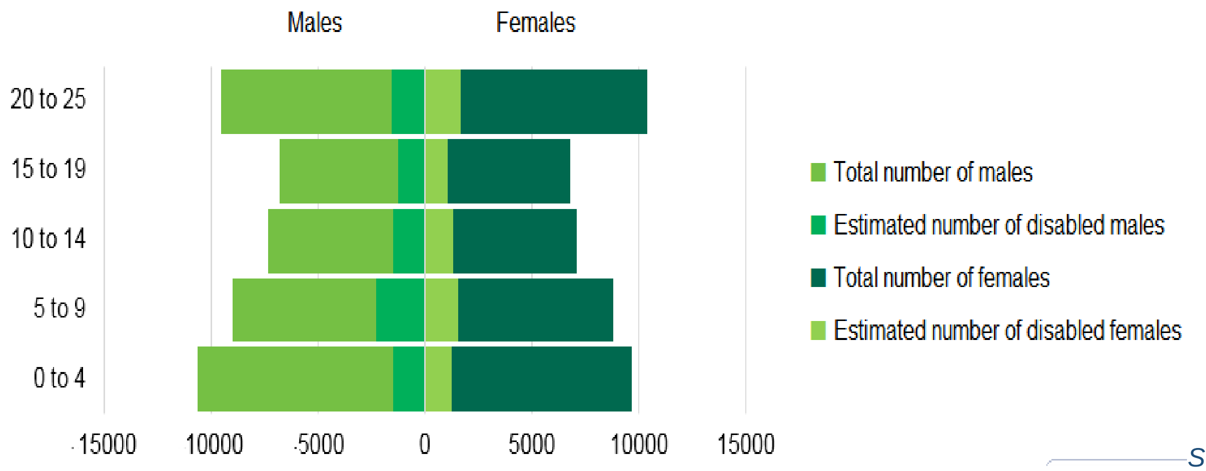
7.1.1 Population and estimated prevalence of disability

The Office for National Statistics (ONS) mid-year estimate of the Hackney population for 2015 is 269,000. [58] The Greater London Authority (GLA) household 2016 population estimate for Hackney is slightly higher at 271,100. [59] This value is taken from the Strategic Housing Land Availability Assessment (SHLAA), and may be differ from the actual population total as it rounds figures to the nearest 100 and takes housing growth into account (see Methodology and Limitation section 22.2 for further details). This document will use the GLA estimate of 271,100

Approximately a quarter of the Hackney population is under 20 years old (24.3%), and only 18% of the population are over 55 years old. The estimated number of males and females living in Hackney is roughly equal, with 135,200 males and 135,700 females. However, there are more boys aged 0-14 than girls (as shown in Figure 5 and Figure 6), and more women aged 50 and over than men. The total number of those aged 0-24 in Hackney is estimated to be 86,000 for the year 2016. For a breakdown of the Hackney population for all ages with regards to numbers, gender, ethnicity and deprivation please refer to the Hackney and the City JSNA document (Chapter 1: the people of Hackney and the City).

Figure 5 also shows the estimated gender and age specific number of disabled children in Hackney in 2016.

Figure 5: Gender and age specific estimates of Hackney total population, and estimated disabled population for 2016



Source: Population Data. GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59] Rates of age-specific disability from National Child and Maternal Health Intelligence Network Disabled Children's Needs Assessment [60] and Papworth Trust: Disability Facts and Figures [4]

Figure 6: Current Hackney population with age and gender specific numbers and percentages for 2016.

	Males			Females		
Age in Years	Number	Percentage of the total population	Percentage of the total male population	Number	Percentage of the total population	Percentage of the total female population
0-4	10,600	3.9%	7.8%	9,700	3.6%	7.1%
5-9.	9,000	3.3%	6.7%	8,800	3.2%	6.5%
10-14.	7,300	2.7%	5.4%	7,100	2.6%	5.2%
15-19	6,800	2.5%	5.0%	6,800	2.5%	5.0%
20-24	9,500	3.5%	7.0%	10,400	3.8%	7.7%
Total 0-24	43,200	15.9%	31.9%	42800	15.7%	31.5%
Total Population 0-24		86000				

Source: GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59]

7.1.2 Ethnicity

The latest census in 2011 revealed that the proportion of the Hackney population who classify themselves as White British is just over a third at 36.2% as shown in Figure 7. [61] As

Figure 8 visually displays and

Figure 9 outlines, this is lower than the proportion of White British people in City of London, London as a whole or England. Within Hackney the second largest ethnic group is Black African/Caribbean/British at 23.1% of the population. [62]

Hackney has a large Orthodox Jewish (Charedi) population. The Charedi Jewish population is the second largest in Europe and represents 7.4% of Hackney's population. The majority live in the North-East of the borough. [63] Of note, the Charedi population is rapidly increasing secondary to high birth rates, with the average rate of 5.9 children per family compared to the average of 1.7 children per family across the United Kingdom. [64] The high birth rate helps to explain the fact that over half (53.5%) of the Charedi population are aged 19 and under, over double the proportion of children and young people in the general Hackney population (24.3%). Charedi children are estimated to make up 20% of all children in Hackney.

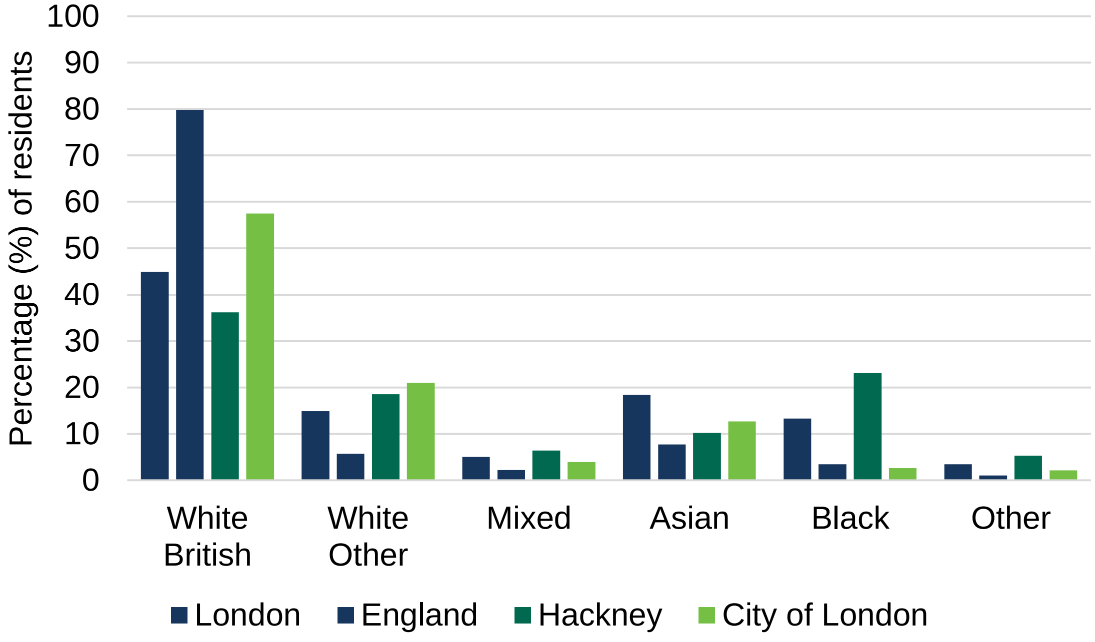
Figure 7: Hackney 2011 Census Ethnic group data

Ethnic Group	Ethnic Subgroup	Number of people	Percentage of population
White	**Total**	**134,617**	**54.7%**
	English/Welsh/Scottish/ Northern Irish/British	89,030	36.2%
	Irish	5,216	2.1%
	Gypsy or Irish Traveller	474	0.2%
	Other White	39,897	16.2%
Mixed/multiple ethnic groups	**Total**	**15,869**	**6.4%**
	White and Black Caribbean	4,989	2.0%
	White and Black African	2,866	1.2%
	White and Asian	3,020	1.2%
	Other Mixed	4,994	2.0%
Asian/Asian British	**Total**	**25,867**	**10.2%**
	Indian	7,599	3.1%
	Pakistani	1,905	0.8%
	Bangladeshi	6,180	2.5%
	Chinese	3,436	1.4%
	Other Asian	6,747	2.7%
Black/African/Caribbean/ Black British	**Total**	**56,858**	**23.1%**
	African	27,976	11.4%

	Caribbean	19,168	7.8%
	Other Black	9,714	3.9%
Other Ethnic group	**Total**	**13,059**	**5.3%**
	Arab	1,721	0.7%
	Any other ethnic group	11,338	4.6%
All usual residents	**Total**	**246,270**	**100%**

Source: 2011 Census data [65]

Figure 8: Ethnicity of population as a percentage of residents



Source: 2011 Census [66]

Figure 9: Ethnic group of residents as a percentage for Hackney, City of London, London and England

Ethnic Group	Ethnic Subgroup	Hackney	City of London	London	England
White	**Total**	**54.7%**	**78.6%**	**59.8%**	**85.5%**
	English/Welsh/Scottish/ Northern Irish/British	36.2%	57.5%	44.9%	79.8%
	Irish	2.1%	2.4%	2.2%	1.0%
	Gypsy or Irish Traveller	0.2%	0.04%	0.1%	0.1%
	Other White	16.2%	18.6%	12.6%	4.6%
Mixed/ multiple ethnic groups	**Total**	**6.4%**	**3.9%**	**5.0%**	**2.2%**
	White and Black Caribbean	2.0%	0.5%	1.5%	0.8%
	White and Black African	1.2%	0.5%	0.8%	0.3%
	White and Asian	1.2%	1.5%	1.2%	0.6%
	Other Mixed	2.0%	1.4%	1.5%	0.5%
Asian/Asian British	**Total**	**10.2%**	**12.7%**	**18.4%**	**7.7%**
	Indian	3.1%	2.9%	6.6%	2.6%
	Pakistani	0.8%	0.2%	2.7%	2.1%
	Bangladeshi	2.5%	3.1%	2.7%	0.8%
	Chinese	1.4%	3.6%	1.5%	0.7%
	Other Asian	2.7%	2.8%	4.9%	1.5%
Black/African/ Caribbean/ Black British	**Total**	**23.1%**	**2.6%**	**13.3%**	**3.4%**
	African	11.4%	1.3%	7.0%	1.8%
	Caribbean	7.8%	0.6%	4.2%	1.1%
	Other Black	3.9%	0.7%	2.1%	0.5%
Other Ethnic group	**Total**	**5.3%**	**2.1%**	**3.4%**	**1.0%**
	Arab	0.7%	0.9%	1.3%	0.4%
	Any other ethnic group	4.6%	1.2%	2.1%	0.6%

Source: 2011 Census

7.1.3 Deprivation

Deprivation is linked to disability in a two-way relationship. Disabled children are amongst the most likely to experience poverty, and children from poorer backgrounds are more likely to become disabled than those who are better off. [4] Nationally there are lower rates of disability in areas with low levels of deprivation and higher rates of disability in areas with higher levels of deprivation. [67]

Local authorities in England are ranked according to the Index of Multiple Deprivation. This takes into account measures of deprivation within the areas of: health, education, income, employment, housing and access to services, living environment and crime. In 2010 Hackney was ranked as the second most deprived local authority in England, however the most recent measure in the 2015 Index of Multiple Deprivation its ranking had improved to eleventh most deprived. [68] Despite this improvement, Hackney is still the most deprived local authority when compared to its ten statistical peers. The closest in deprivation was Islington which was ranked as twelfth most deprived. The proportion of children living in deprived households in Hackney ranks tenth highest in the country at 32%; almost a third of children in the borough encountering deprivation.

The Child Wellbeing Index published in 2009 aimed to measure local child wellbeing and markers of deprivation with regards to factors such as maternal wellbeing, education, housing and crime. Hackney ranked 352nd overall out of 354 local authorities, with only two local authorities showing higher levels of child deprivation. It was ranked as having the highest level of child deprivation of all its statistical peers as displayed in Figure 10 below. [69] However, this was based on 2005 data.

Figure 10: Local Authority Ranking on the Child Wellbeing Index

Local Authority	Ranking on Child Wellbeing Index
Enfield	268
City of London	284
Hammersmith and Fulham	331
Waltham Forest	333
Brent	334
Greenwich	335
Haringey	340
Lewisham	342
Lambeth	348
Southwark	350
Islington	351
Hackney	352

Source: Local Index of Child Well-Being. Communities and Local Government. 2009 *[69]*

7.1.4 Population Projections

The Greater London Authority produces future population estimates, taking future housing growth into account from the SHLAA. These projections are updated annually and are currently available for the next 25 years, up to 2041. Figures are rounded to the nearest 100. *Figure 11* shows the projected gender and age specific population change for Hackney for 2020, 2025 and 2030 compared to the current estimated 2016 population. As shown there is predicted to be growth across all age groups for those 0 to 24 by 2030, however there is predicted to be a decrease in the age 20 to 24 bracket for both males and females initially.

Figure 11: Estimated percentage change in age and gender specific population compared to 2016 estimates

	Projected population 2020		**Projected population 2025**		**Projected population 2030**	
Age	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**
0-4	1.9%	4.1%	8.5%	10.3%	9.4%	12.4%
5-9	5.6%	1.1%	10.0%	5.7%	15.6%	10.2%
10-14	11.0%	14.1%	20.5%	16.9%	24.7%	21.1%
15-19	0.0%	1.5%	13.2%	16.2%	22.1%	19.1%
20-24	-1.1%	-4.8%	-2.1%	-4.8%	8.4%	5.8%

Source: GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59]

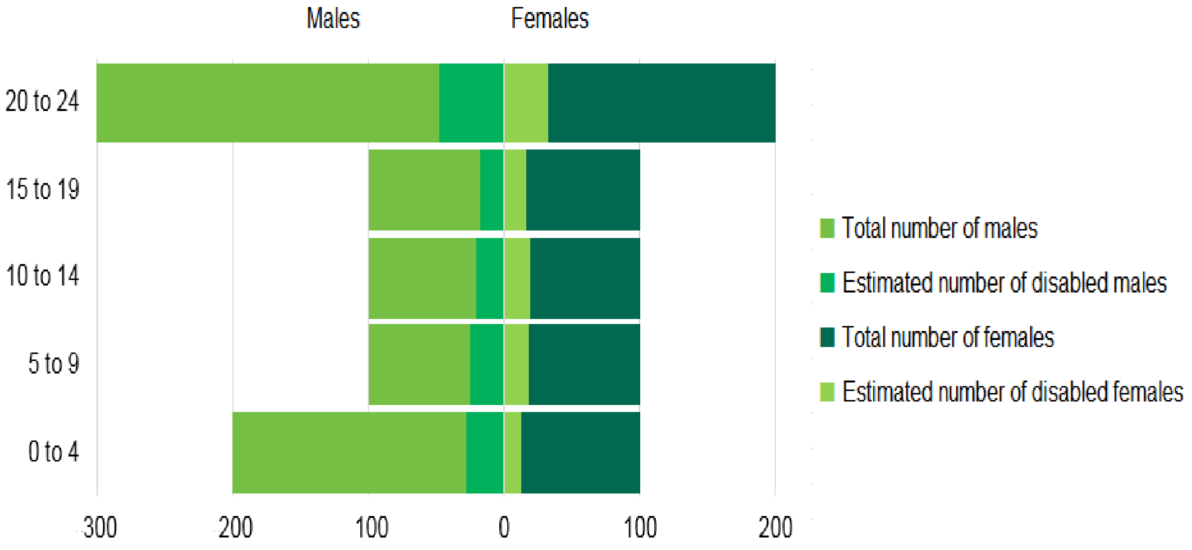
7.2 City of London

The City of London is just over one square mile in size and is the heart of business within the area and provides employment to over 400,000 people. However, the number of residents living within the area are far fewer, with the ONS mid-year estimate for 2015 of 8,760. [70] The Greater London Authority estimate of the 2016 population, when taking housing growth into account is 8,500. [59] For consistency in this Needs Assessment the GLA estimates will be utilised for both Hackney and the City of London.

7.2.1 **Population and estimated prevalence of disability.**

Compared to Hackney where a quarter of the population is under 20, those aged 0-19 only make up 10.8% of City of London residents as displayed in *Figure 13*. The majority of residents of the City of London are aged between 20 and 55, with 12.2% of the population over 55 years old (compared to 14% of the population of Hackney). The ratio of males to females across all ages is approximately 2:3 unlike Hackney, where the gender split is almost equal. However, population estimates are figures to the nearest 100, therefore the accuracy of this gender discrepancy comes into question. The population per gender for those aged 0 to 24 is displayed in Figure 12 along with the estimated age and gender specific prevalence of disability.

Figure 12: Gender specific current population estimate and estimated disabled population for the City of London for 2016



Source: Population Data. GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59] Rates of age-specific disability from National Child and Maternal Health Intelligence Network Disabled Children's Needs Assessment [60] and Papworth Trust: Disability Facts and Figures [4]

Figure 13: Age and gender specific current estimated population and estimated disabled population for 2016

Source: GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016)

	Males			Females		
Age in Years	Number	% of total population	% male population	Number	% of total population	% female population
0-4	200	2.4%	4.2%	100	1.2%	2.7%
5-9.	100	1.2%	2.1%	100	1.2%	2.7%
10-14.	100	1.2%	2.1%	100	1.2%	2.7%
15-19	100	1.2%	2.1%	100	1.2%	2.7%
20-24	300	3.5%	6.3%	200	2.4%	5.4%
Total 0-24	800	9.5%	15%	600	7.2%	13.2%
Total 0-24 population	1400					

[59]

7.2.1 Ethnicity

Unlike the Hackney population, over half of City of London residents are White British (57.5%). [71] If including those who classify themselves as Other White and Irish, 78.6% of the resident population self-classify as White as seen in .

Figure 14 below. The next most common ethnic group is Asian/Asian British at 12.7% of residents. The ethnic makeup of City of London residents is compared to that of Hackney, Greater London and England in

Figure 8.

Figure 14: City of London 2011 Census Ethnic Group Data

Ethnic Group	Ethnic Subgroup	Number of people	Percentage of population
White	**Total**	**5,799**	**78.6%**
	English/Welsh/Scottish/ Northern Irish/British	4,243	57.5%
	Irish	180	2.4%
	Gypsy or Irish Traveller	3	0.04%
	Other White	1,373	18.6%
Mixed/multiple ethnic groups	**Total**	**289**	**3.9%**
	White and Black Caribbean	38	0.5%
	White and Black African	37	0.5%
	White and Asian	111	1.5%
	Other Mixed	103	1.4%
Asian/Asian British	**Total**	**940**	**12.7%**
	Indian	216	2.9%
	Pakistani	16	0.2%
	Bangladeshi	232	3.1%
	Chinese	263	3.6%
	Other Asian	213	2.8%
Black/African/Caribbean/ Black British	**Total**	**193**	**2.6%**
	African	98	1.3%
	Caribbean	46	0.6%
	Other Black	49	0.7%
Other Ethnic group	**Total**	**154**	**2.1%**
	Arab	69	0.9%
	Any other ethnic group	85	1.2%
All usual residents	**Total**	**7,375**	**100%**

Source: Census 2011 [72]

7.2.2 Deprivation

Unlike Hackney, City of London is relatively affluent when measured against the Index of Multiple Deprivation. It ranks at 226 out of 326 local authorities in England, and is within the third least deprived in London. [73] However on the Local Index of Child Wellbeing the City of London ranks as 284th out of 354, as shown in Figure 10. Although this is higher than Hackney and the other local authorities in the London Cosmopolitan subgroup, it is still within the bottom third of local authorities for Child Wellbeing. [69]

7.2.3 Projections

The GLA all age population estimate for City of London in 2016 is 8500. This figure is small compared to other local authorities, and as figures are rounded to the nearest 100, changes in projected population that may not be large enough to influence this rounded figure, therefore are not visible. The only group in which there is an estimated projected population increase in under 25 year olds by the year 2025 is males aged 15-19 which are predicted to rise to 200. The remaining age and gender specific groups in the under 25 year old population are predicted to be unchanged.

8 Prevalence of disability

8.1 Estimates of number of disabled children in Hackney and the City

Estimating the number of disabled children that are within the population of a local authority is important when trying to assess whether there are children who are not being identified by local systems and services. Estimates are also important when planning future service provision. Estimates of the prevalence of disability in children and young people vary dramatically depending on data source used, as displayed in Figure 16.

Figure 15: Estimated number of disabled children in Hackney and the City of London by prevalence rate source

Prevalence Source	Estimated percentage of disabled children in Hackney	Estimated number of disabled children in Hackney in 2016	Estimated number of disabled children in City of London
Thomas Coram Research Unit (2008)	3.0-5.4% (aged 0-18)	1,899-3,418	27-49
Blackburn et al (2010)	7.3% (aged 0-18)	4,621	66
Office of National Statistics (2000)	19.11% for males 17.05% for females (aged 0-19)[5]	11,962	140
Papworth Trust (2013)	16% Working age adults (20-24)	3,184	80

Source: Prevalence estimates from the National Child and Maternal Health Intelligence Network. Population estimate from GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections [59]

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[5] The 19.11% for males includes 19% having a longstanding illness or mild disability and 0.11% having a severe disability. For females aged 0-19. 17% are estimated to have a long-standing illness or mild disability and 0.05% are estimated to have a severe disability.
Longstanding illness/mild disability was classified into the following impairment categories: Mental Disorders, Learning Difficulties, Nervous System Disorders not elsewhere specified, Blindness/Vision Defects, Deafness/Ear Defects, Heart Disease, Lug/Respiratory Disease, Asthma, Digestive Disorders, Urogenitary Disorders, Musculoskeletal Problems, Skin Conditions and Physical Handicap.
Severe Disabilities were classified into the following impairment categories: Asthma, Autism, Behavioural disorders, Cancer/Tumours, Cerebral Palsy, Deafness, Down's Syndrome, Epilepsy, Global Developmental Delay, Mental Handicap and Central Nervous Disorders not otherwise specified.

The methodology used to calculate these estimated prevalence rates are discussed in the Methodology chapter, section 22.3. The highest estimate will be utilised throughout the remainder of this Needs Assessment (ONS 2000 in Figure 15 above).

This prevalence estimate has been chosen as it gives age and gender specific estimates. Although this is the highest estimated prevalence rate, it is the closest to the national school census percentage of pupils known to have Special Educational Needs and Disabilities. It is also most likely to include all levels and types of disability. For those aged over 19 the Papworth Trust estimate of 16% of working age adults having a disability will be used. [4]

Utilising the National Child and Maternal Health Intelligence Network, Office of National Statistics prevalence rate [74] and applying this to the estimated 2016 population values from the GLA provides an estimate of 11,962 disabled children and young people aged 0-19 in Hackney and 140 in the City of London. For those aged 20-24 a total of 3,263 adults are estimated to have a disability in Hackney and the City of London.

This leads to a total estimate of 15,366 disabled children and young people aged 0-24 in Hackney and the City of London.

8.2 Known to local services

As demonstrated by the varying prevalence estimates above, accurately estimating or measuring the number of disabled children in the population is problematic. There is no one national register or database that is guaranteed to capture every child with a disability. Numbers of disabled children can be captured via healthcare records (with Read Coding, ICD-10 coding, DSM-5 coding and SNOMED coding), via schools reporting the number of children with special educational needs and disabilities on the school census, or via national surveys and questionnaires which rely on self-reporting (such as the Family Resources Survey [75]). The definition of disability often varies between different organisations, so the disabled population captured by each will vary.

8.2.1 School Special Educational Needs and Disability data

Schools submit data annually via the school census which includes information on children with special educational needs and disabilities (SEND). This captures both children with SEN support and those with a statement of SEN or Education, Health and Care plans. Children with SEN support are those who are adequately assessed and supported within their school. A common reason for a child requiring SEN support is dyslexia for example. Children who have Educational Health Care plans (EHC) or Statements of Special Educational Needs have educational needs which cannot be met by the school without additional input. Combining the number of pupils with both SEN support, statements of SEN and EHC plans is most likely to capture all those with disabilities known to schools.

Parents can request a local authority to carry out an EHC plan assessment if they feel their child requires one. The child or young person can request an assessment themselves if they are aged 16 to 25. In addition, professionals whether in health, education or social care can request an assessment. If after assessment a decision is made to give an EHC plan, the final plan should be completed within 20 weeks of assessment. Reports and assessments from education, healthcare and others may be included in the decision making process.

Special Education Need support (SEN support) = pupils who have additional education needs which the school is able to assess and support.

Statement of Special educational Needs (statement of SEN) = pupils who have additional educational needs which the school cannot support without additional input. No new statements of SEN are being issued as these have been replaced with EHC plans.

Education, Health and Care plans (EHC plans) = the new replacement for statements of SEN. All pupils with statements of SEN should be converted to EHC plans by April 2018.

Total known to have Special Educational Needs and Disabilities within schools

The most recent 2016 school census established that 14.4% of school children in England have SEND, with 2.8% having a statement or EHC. [76] This gives a total of 17.2% of pupils with Special Educational Needs or Disabilities.

Locally, this data shows 18.5% (n=6,312) of children in state-funded schools in Hackney have special educational needs. The majority of these children (3,377 in primary schools and 2,605 in secondary schools) are in mainstream education, with 330 children (5% of those with special educational needs in Hackney state-funded schools) attending state-funded special schools in Hackney.

Hackney has the highest percentage of children attending state-maintained primary (2.6%) and secondary schools (3%) with statements of SEN or EHC plans compared to its ten statistical peers. The percentage of children in state-maintained primary schools receiving SEN support (different to statements of SEN) is 13.6%, this is higher than the London and England average, however is joint fifth lowest of its statistical peers. The percentage of those receiving SEN support within state-maintained secondary schools is 17.3%, the second highest within the group of statistical peer local authorities.

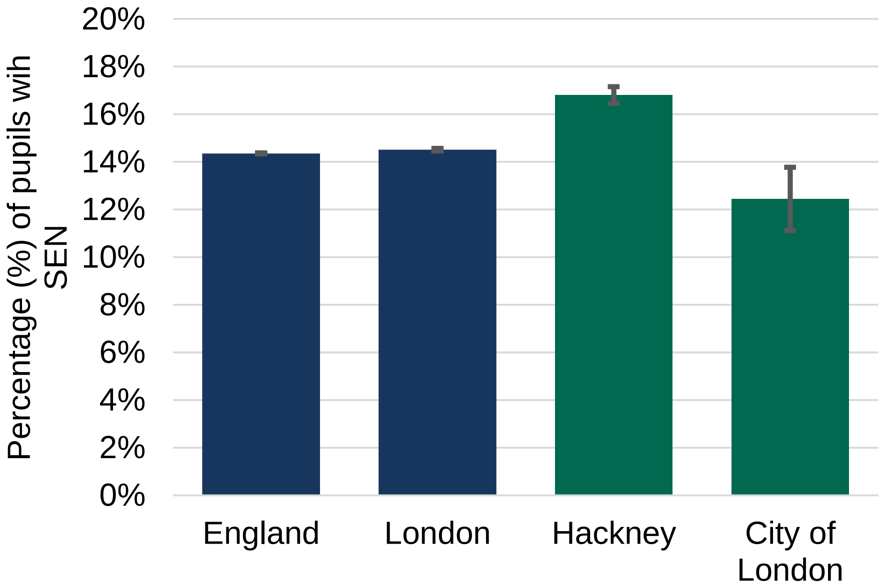
City of London has one state-funded primary school. There are 47 children attending the state-funded primary school who have special educational needs. This consists of a total of 40 pupils receiving SEN support (16% of pupils) and 7 with a statement of SEN or EHC plan (2.8% of pupils).

The raw ‘all school’ numbers of children with statements of SEN and EHC plans, and those who have SEN but do not have a statement, are also available.[6] However, the data for number and proportion with each primary type of need is only available for state-funded schools. The all school data is not categorised into primary, secondary and special schools, therefore it is not possible to comment on age-specific needs. Utilising the all school data, there are 1,461 children in Hackney with an EHC plan or statement of SEN (3.4% of pupils), and 5,830 receiving SEN support (13.4% of pupils) giving a total of 16.8% of pupils across all Hackney schools as having special educational needs. This implies that there are at least 979 children with special educational needs who are not in state-funded schools. The ‘all school’ data does not take into consideration unregistered schools. Locally this is of relevance as a proportion of the relatively closed communities (such as the Charedi population) are likely to not be attending state-funded schools. Therefore the SEND needs of these communities will not be reflected in SEND data. For this reason it is likely that there is a greater proportion of pupils with SEND than displayed in Figure 16.

The total number of pupils with SEND within all City of London schools is 293, with 8 pupils having statements of SEND or EHC plans (0.3% of pupils) and 285 receiving SEN support (12.2% of pupils).

As displayed in Figure 16, Hackney has the highest percentage of pupils with special educational needs across all school when compared to England, London and the average value for its group of statistical peers.

Figure 16: All school percentage (%) of pupils with special educational needs.[7]



Source: Department for Education. Special Educational Needs in England: 2016 [76]

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[6] Includes maintained and direct grant nursery schools, maintained primary and secondary schools, city technology colleges, university technology colleges, studio schools, primary and secondary academies including free schools, special schools, special academies including free schools, general hospital schools, pupil referral units, alternative provision academies including free schools and independent schools.

[7] Standard error bard with 95% confidence intervals included.

Primary type of need

Children with special educational needs and disabilities in schools are classified by their ‘primary type of need’, this is classified into 13 categories.[8] If a pupil has more than one type of need they will be categorised by that which impacts on their learning and education most significantly.

The primary SEN needs of children within Hackney state-funded schools varies between primary, secondary and special schools, as seen in Figure *17*. The majority of children with special educational needs within mainstream primary schools have speech, language or communication needs. This differs from secondary schools where moderate learning disabilities and social, emotional and mental health difficulties are the primary need for over half of pupils. The most common primary type of need within state-funded special schools is Autistic Spectrum Disorder at approximately 40%. Sensory impairments (whether visual, hearing or multi-sensory impairment), when combined are the primary need for less than 1 in 20 children (5%) of children in primary, secondary or special schools.

As there is only one state-funded primary school within City of London it is not possible to present SEN in greater detail without a risk of potentially identifiable data. However, overall the most common primary type of need in the City of London primary school was Specific Learning Disability which include conditions such as dyslexia, whereas in Hackney the most common was Speech, Language and Communication which can be a need in a wide range of conditions.

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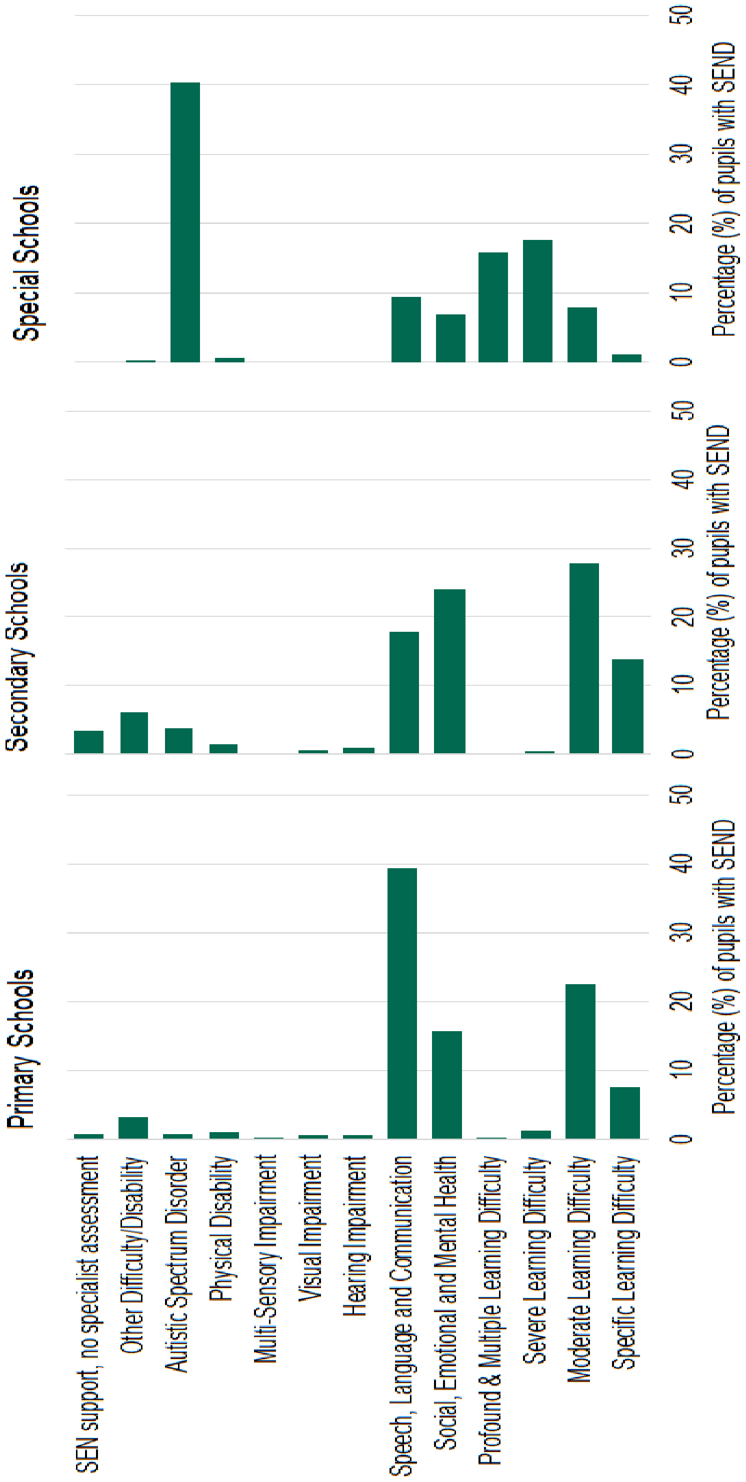
[8] Specific Learning Difficulty; Moderate Learning Difficulty; Severe Learning Difficulty; Profound and Multiple Learning Difficulty; Social, Emotional and Mental Health; Speech, Language and Communication; Hearing Impairment; Visual Impairment; Multi-Sensory Impairment; Physical Disability; Autistic Spectrum Disorder; Other Difficulty/Disability; SEN support, no special assessment required.

Figure 17: Percentage of pupils in state-maintained schools in Hackney and the City of London with SEN for each primary type of need[9]



Source: Department for Education. Special Educational Needs in England: 2016 [76]

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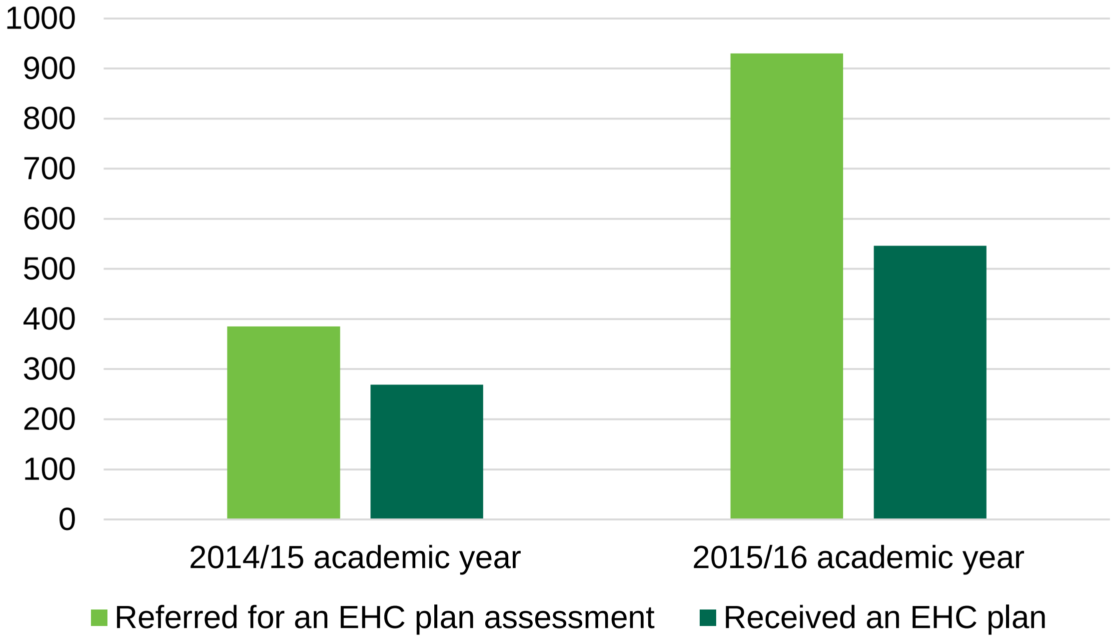
[9] Specific Learning Disability refers to difficulties such as dyslexia, dyscalculia and dyspraxia.

Education, Health and Care Plan data

Data from Hackney Learning Trust has shown an increase in the number of children referred for an Education, Health and Care Plan (EHC plan), and an increase in the number of those receiving an EHC plan in the last two years.

In the 2014/15 academic year 385 children were referred for an EHC plan, of whom 269 received an EHC plan (70%).
In the 2015/16 academic year the demand on the service increased as shown in Figure 18. The number of referrals for assessment more than doubled, and 930 children were referred. Of the 930 children referred, 546 children received an EHC plan (59%).

Figure 18: Number of those referred for an EHC plan assessment and those receiving an EHC plan in the 2014/15 and 2015/16 academic years in Hackney.



Source: Hackney Learning Trust (2016)

8.2.2 ‘The Key’ Hackney Children’s Disability Register

The Key is a voluntary register for disabled children in Hackney. Every area has a statutory duty to provide a register of disabled children, however it is voluntary for people to sign up and is not related to any support available to families. Parents of disabled children or disabled young people can choose to register and self-refer. The aim was so that the Borough of Hackney could utilise this information for local service planning and allocation of resources. There are currently 754 children on the register. The Disabled Children’s team report that the majority are receiving Short Breaks services, therefore receiving middle or high rate Disability Living Allowance. The reliability of this data source has not been legitimised. Numerous demographic details are missing in the database as discussed in the Methodology chapter, section 22.3.4. For this reason the data will only be utilised in one inequalities section of this report.

8.2.3 The City of London Children's Disability Register

The City of London have a disability register which follows a similar format to that in Hackney. They provide families the opportunity to register themselves online as well as in person.

Hackney Special Educational Needs and Disability Team (2016) [146] Children's disability register UK.

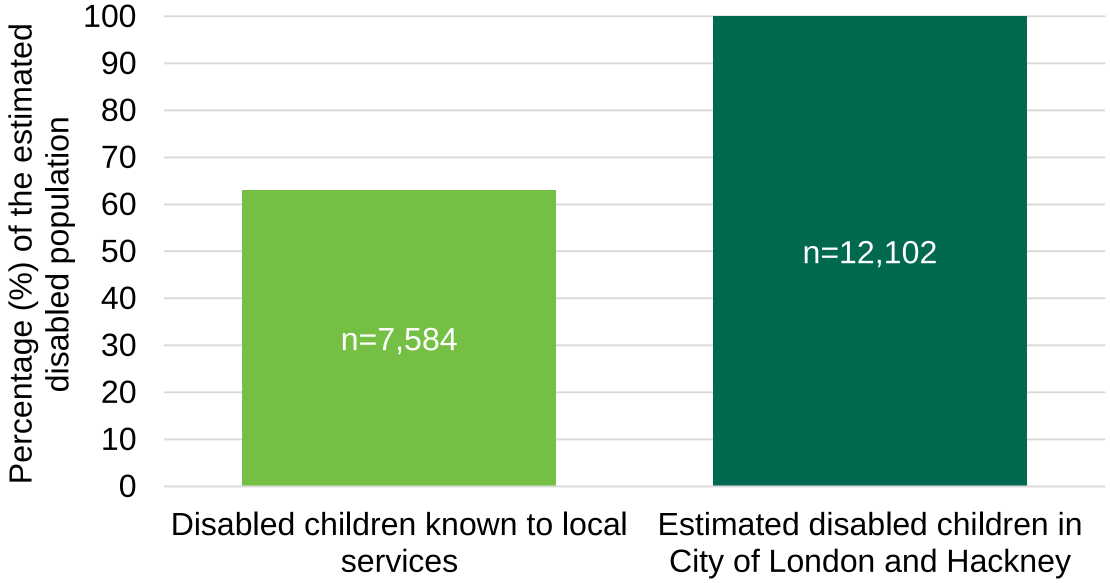
8.3 Unmet Need

By comparing the number of those with disabilities to the estimated prevalence of disabled children and young people we can identify potential unmet need.

The estimated number of disabled children and young people aged 0-19 in Hackney and the City of London is 12,102 (rates given in Section 8.1) [60].

The school census data for 2016 found 1,469 pupils across all Hackney and City of London schools had a statement of Special Educational Needs or an EHC plan, and 6,115 receiving SEN support. This total of 7,584 is 4,518 lower than the estimated disabled population. Therefore 37% of the estimated disabled population may not be known to services as shown in Figure 19. However, as mentioned in Section 3 the definition of disability varies, and those receiving SEN support include children and young people with a wide range of needs, who may not all meet the Equality Act (2010) definition of disability.

Figure 19: Percentage (%) of the estimated disabled population known to local services[10]



Source: National Child and Maternal health Intelligence Network and 2016 School Census data.

8.4 Inequalities

Inequalities refer to preventable and unjust differences in health status experienced by certain groups within the population. When discussing inequalities throughout this needs assessment, it will be with reference to gender, age, ethnicity, deprivation and disability

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[10] n= total number of children.

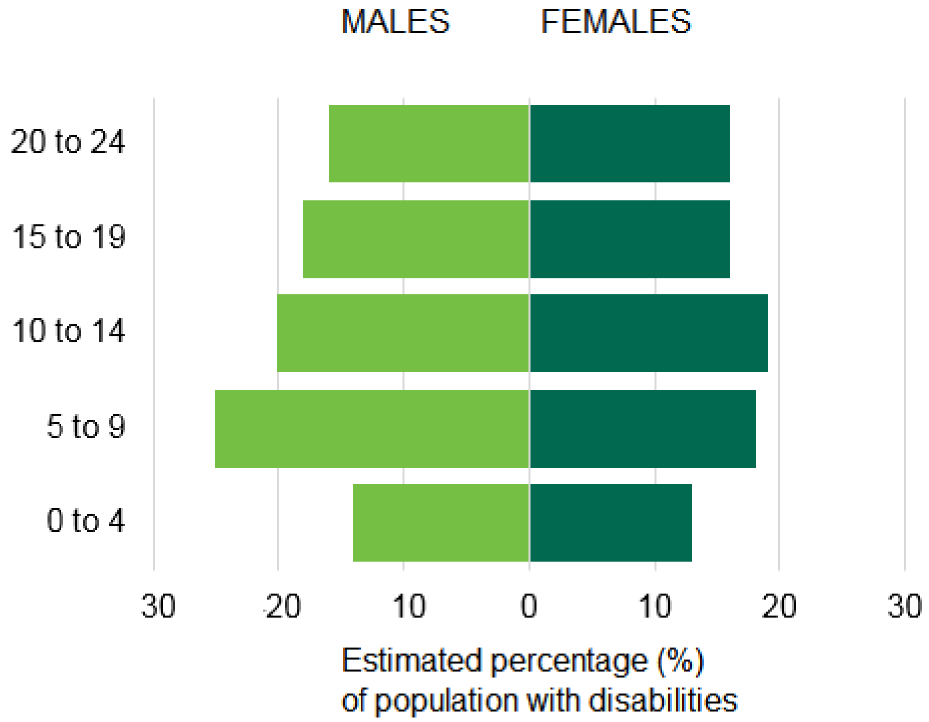
where this information is available. For some data not all of these characteristics will be available and this will be stated.

8.3.1 Gender and age

The estimated prevalence of disability is higher for males than females aged 0 to 19 as is displayed visually in Figure 20 and broken down in Figure 21.

Figure 21 shows that for all age groups the number of children with mild disability is estimated to be higher for males than for females. This gender difference is also seen to a larger extent in Figure 21, which outlines age and gender specific estimates of severe disabilities. Another observation is that unlike for mild disability the rate of severe disability is highest in the 0-4 age group. This is likely to be multi-factorial but a possible reason for this is that many severe disabilities can be diagnosed during antenatal scans, such as spina bifida, or very early in life (during routine neonatal examination); mild disabilities may either develop as the child gets older, or be identified later. Another possible cause of this difference between age groups may be that some severe disabilities may greatly reduce life expectancy and that some children with severe disabilities may not survive beyond 0 to 4 years of age.

Figure 20: Percentage of estimated disability per age group and gender.



Source: Rates of age-specific disability from National Child and Maternal Health Intelligence Network Disabled Children's Needs Assessment [60] and Papworth Trust: Disability Facts and Figures [4]

Figure 21: Estimated age-specific percentage of children with a long-standing illness or mild disabilities in Hackney

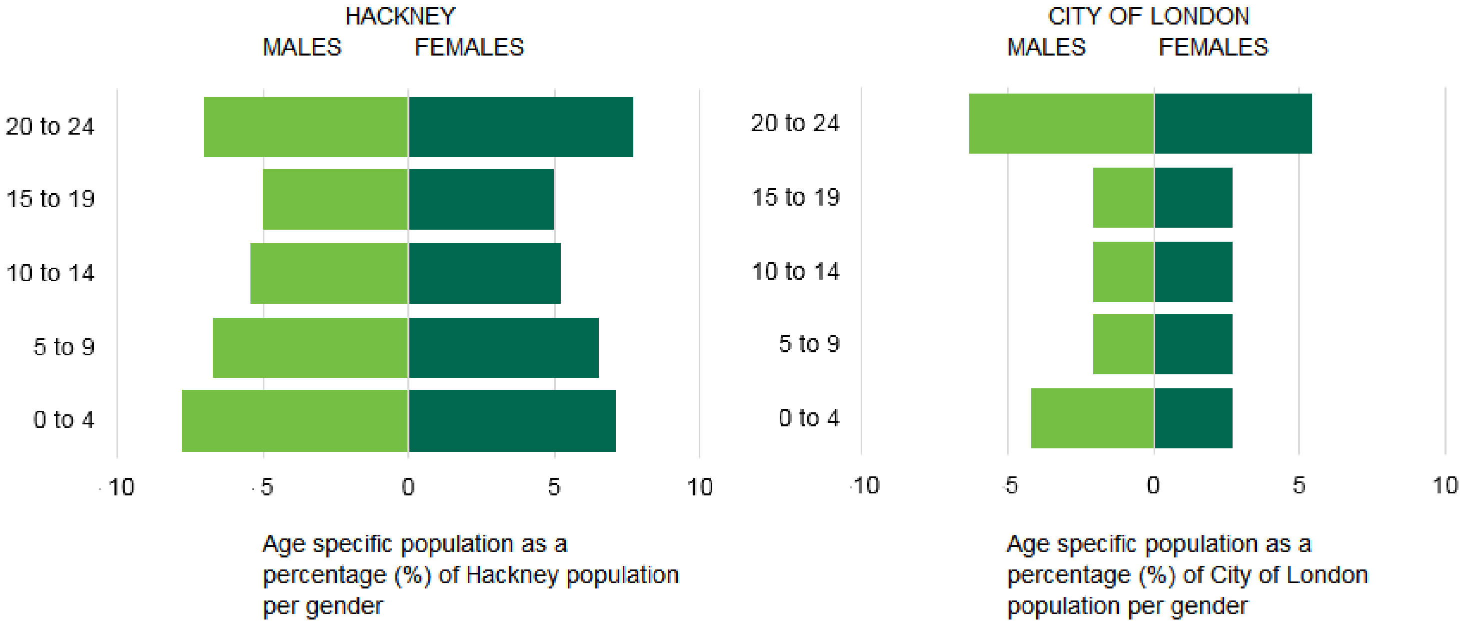
Age	Estimated percentage with long-standing illness/ mild disability		Estimated percentage with severe disability	
	Males	Females	Males	Females
0-4	14%	13%	0.15%	0.08%
5-9	25%	18%	0.12%	0.05%
10-14	20%	19%	0.08%	0.04%
15-19	18%	16%	0.03%	0.02%

National Child and Maternal Health Intelligence Network 2015 age specific prevalence percentages [60]

The age specific estimated prevalence of disability is the same for Hackney and the City of London. However, males aged 0-25 make up a higher percentage of the total male population than females aged 0-25 make-up of the total female population in the City of London. Therefore it would be estimated that significantly more males than females would have a disability in the City of London.

As *Figure 22* demonstrates, the 0-25 year old population of Hackney is a higher proportion of the overall population than 0-25 year olds in the City of London. Therefore disabled children and young people in Hackney would make up a larger proportion of the total population for Hackney than the disabled children and young people in the City do for the total population of the City of London.

Figure 22: Percentage of gender specific population for each age group in Hackney and the City of London as a percentage of the total male population and total female population respectively.

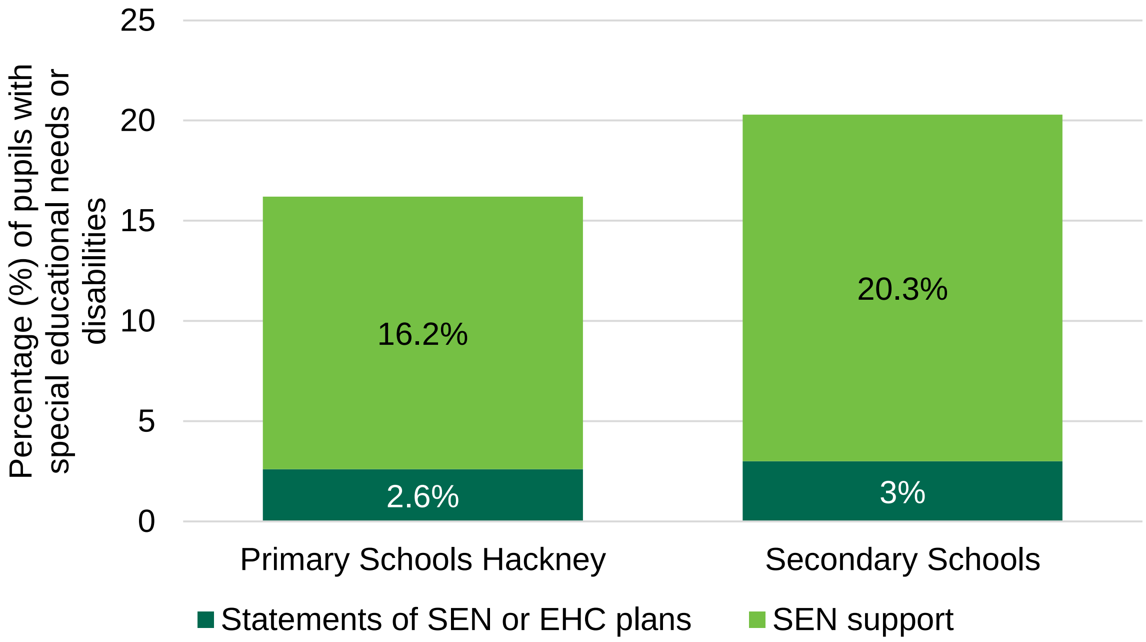


Source: Population Data. GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59]

School census Special Educational Needs and Disabilities data

School census data for state-funded schools does not include nurseries therefore those aged 0 to 4 are not captured. The percentage of pupils with a statement of SEN or EHC plan in state-funded primary and secondary schools in Hackney are similar (2.6% and 3% if pupils respectively). The difference between the proportions receiving SEN support is larger between state-funded primary and secondary schools at 13.6% and 17.3% respectively. This differs from the estimated prevalence rates which are highest for the 5 to 9 age group (primary school age). This implies that there may be under-identification of those with disabilities in the primary school age population.

Figure 23: Percentage (%) of Hackney pupils within state-funded schools with special educational needs or disabilities.



Source: Department for Education. Special Educational Needs in England: 2016 [76]

School census data is not gender specific so the gender split of those identified as having special educational needs and disabilities via the school census is unavailable.

Hackney Learning Trust EHC plan data

In the 2015/2016 academic year, almost three-quarters of the 546 children who received an EHC plan were male (406 children or 74%), whereas only 26% were female.

City and Hackney CCG GP data

Although there is no data available on all those known to GPs as having a disability, data is available for numbers identified as having autism including age and gender demographics. See section 10.5 for this data.

8.3.2 Ethnicity

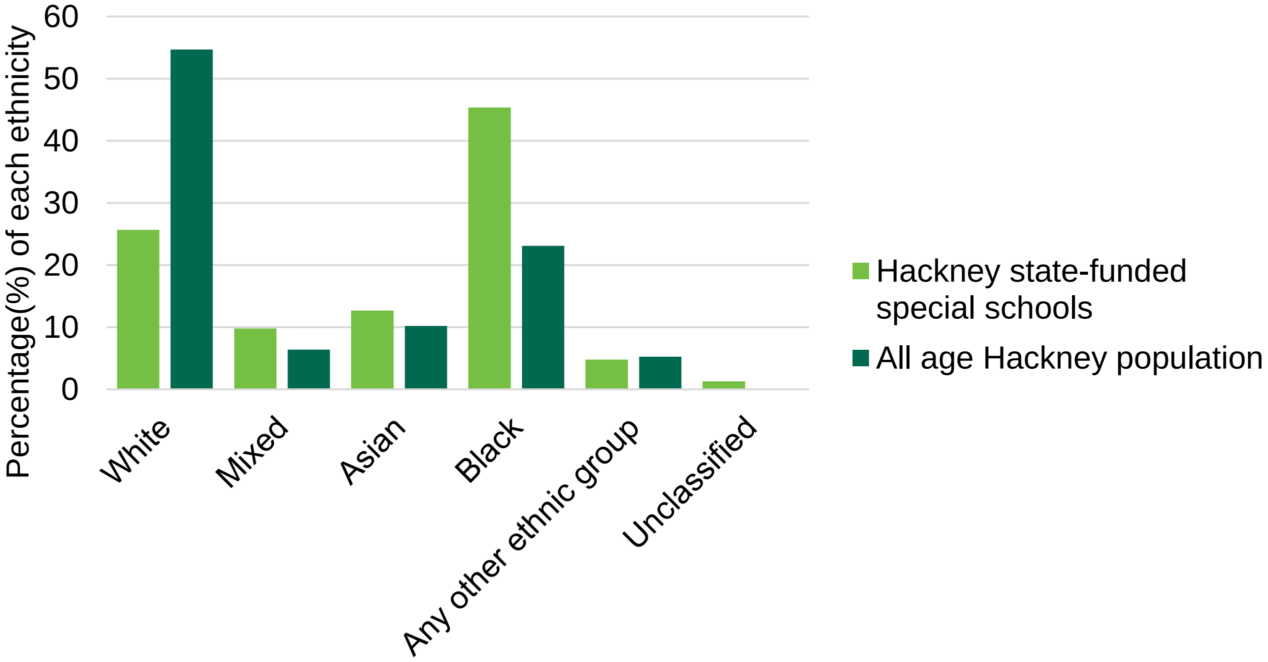
Data on disabled adults suggest that the prevalence of disability varies by ethnicity. In the United Kingdom white adults are the ethnic group which report the highest level of impairments (29% of the adult population), with those of Chinese ethnicity having the lowest reported levels of disability (11%). [4] However other research found that those who identify their ethnicity as black or black British report the highest number of life areas being restricted by their impairment, while those of white ethnicity reported the lowest. [77]

School census

Schools submit ethnicity data as part of the school census. This information is available at a local authority level and is grouped by school type. The present data releases are not able to identify the ethnicity of people with a special educational need or disability.

Ethnicity data for those attending state-funded special schools is available and 100% of those attending special schools have a special educational need or disability.

Figure 24: Ethnicity of pupils attending state-funded special schools in comparison to the ethnicity of the all age total Hackney population.



Source: Special schools: Number of pupils by ethnic group, by local authority area and region in England, January 2016 (2016) Department for Education. All age Hackney population data from the 2011 census.

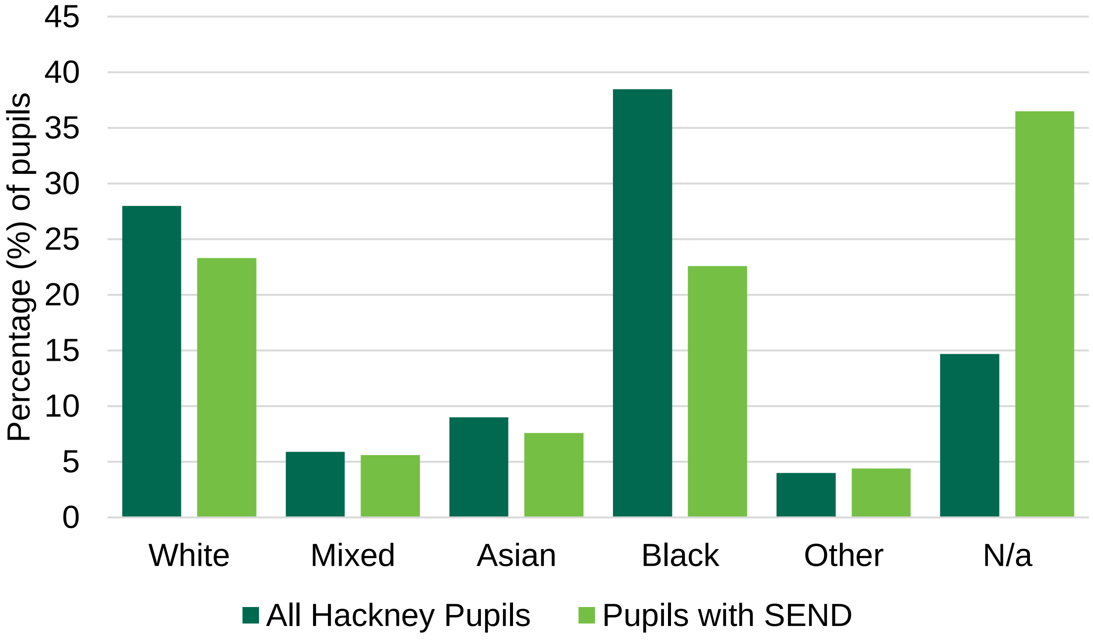
Figure 24 above outlines the ethnicity of pupils attending state-funded special schools in Hackney in comparison to the ethnicity of the total Hackney population. As shown White pupils are under-represented, those from mixed and Asian ethnicities are slightly over-represented and Black pupils make up almost double the proportion of pupils in special schools compared to the proportion of Black residents of Hackney. The detailed ethnic grouping behind the data in Figure 24 can be further divided into the subgroups in Figure 7. The numbers within many of the subgroups are too small to comment upon exact figures and meaningful interpretation of this is limited therefore will not be discussed further. However, the ethnic subgroups with the highest number of pupils in state-funded special schools are Black African, White British and Black Caribbean. Those of Black African and Black Caribbean ethnicity are over-represented in comparison to the proportion of these ethnic groups in the total Hackney population. Those of White British ethnicity are under-represented.

The school census data is not available for City of London as there are no state-funded special schools in the City of London.

Hackney Learning Trust EHC plan data

Ethnicity data is available for the 546 children with an EHC plan in the 2015/2016 academic year in Hackney. Ethnicity data is also available for all pupils attending Hackney schools (both with and without SEND). As shown in Figure 25 below, White pupils are under-represented within the SEND pupil cohort, whereas students of Black ethnicity and Asian ethnicity are over-represented.

Figure 25: Ethnicity of pupils identified as having SEND in comparison to ethnicity of all Hackney pupils for the academic year 2015/16



Source: Hackney Learning Trust (2016)[11]

The Key Hackney Voluntary Disability Register

'The Key' Disabled Children's register includes ethnicity data although as mentioned in Section 8.2.2 the data reliability has not been tested. This source is discussed in this section as the self-reported nature of ethnicity (without using set categories) allows individuals to use the term they prefer to identify their ethnicity. As such it is one of the few source that captures people who self-identify as 'Jewish' as an ethnicity, which is something not routinely captured in reporting despite the unique cultural influence the (specifically orthodox) Jewish community have in the local area. Due to the different ethnicity categories used, different collection methods and unclear validity of The Key data, direct comparison to the school census ethnicity data is not possible.

Ethnicity was recorded for 57.5% (n = 433) of the children and young people on The Key register, the breakdown of which are displayed in Figure 26 below. Those who classify themselves as Black make up over 40% of the children and young people and are over-represented compared to the general Hackney population. Differing from the school census ethnicity data, 'The Key' allowed self-identification to the ethnicity Jewish. Those who self-

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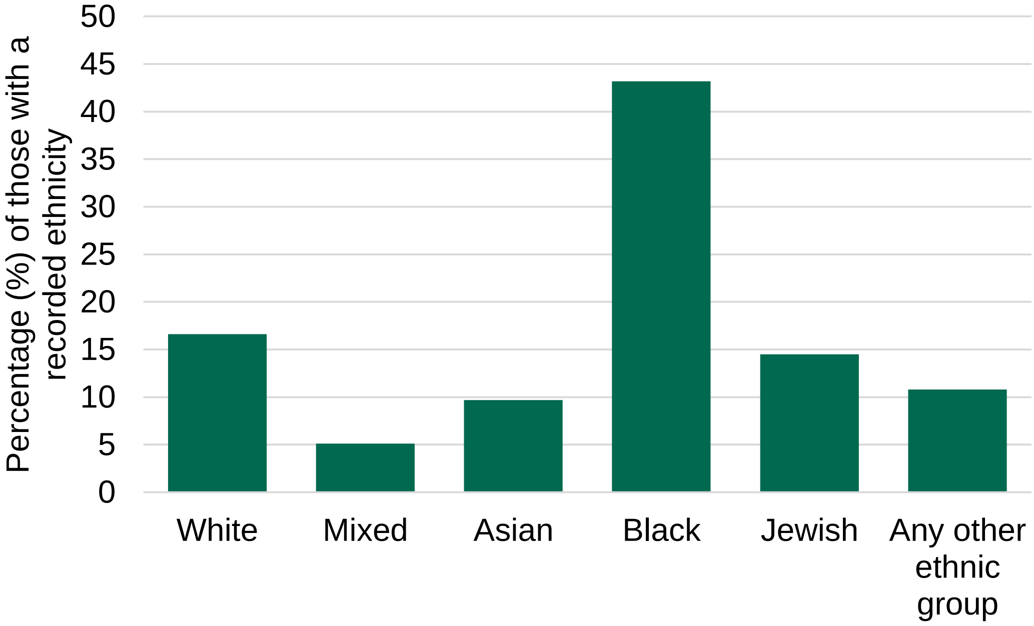
[11] In this graph n/a= Information not yet obtained, refused and N/a

reported as Jewish constitute 14.5% of children and young people on the register. As discussed in Section 7.1.1, 20% of children and young people in Hackney are estimated to be from the Charedi community. It is not possible to comment on whether those from the Charedi community are under-represented on the voluntary disability register as they may have self-classified as White or Any other ethnic group instead, or may have been part of the 42.5% who did not provide information on ethnicity.

Figure 26: Ethnicity of children and young people (0-19) on 'The Key'. Hackney's voluntary disabled register as a percentage of those with a recorded ethnicity.

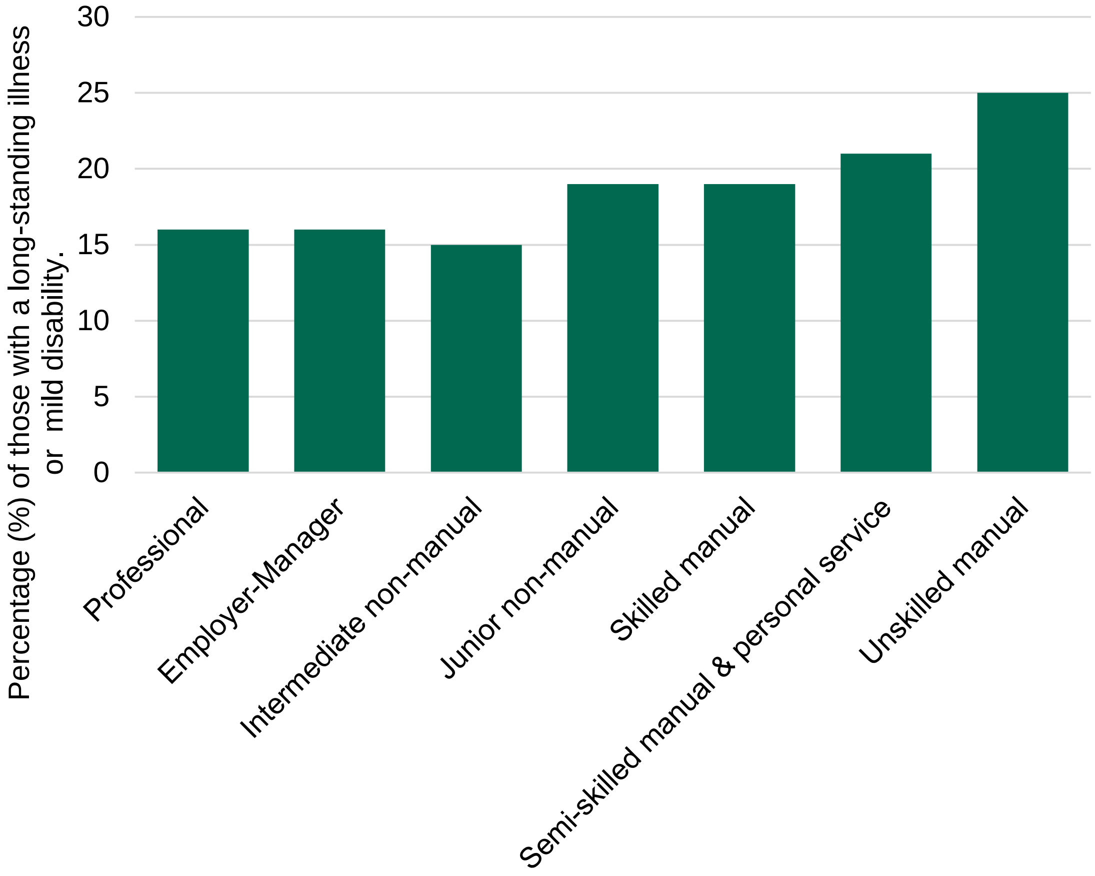


Source: 'The Key' disability register. 2016

8.3.3 **Deprivation**

The ONS utilises the General Household Survey to calculate the percentage of those with a long-standing illness or disability within each socio-economic group. [74] Figure 27 displays the rate of disability was highest in those from families of semi-skilled manual or unskilled manual socio-economic group. The rate of severe disability was found to be greatest amongst children from semi-skilled manual family backgrounds, whilst the lowest rates were for children from professional and managerial family backgrounds. [60]

Figure 27: Percentage of 0-19 year olds in England within each socio-economic group with a long-standing illness or mild disability



Source: ONS, General household survey. [72]

Postcode is often used to identify level of deprivation based on geographical area. Neither postcode nor geographical area below local authority level is available for school census data.

8.3.4 Disability

Undiagnosed disability

Estimates predict the majority of disabled young people with a long-term condition or mild disability are likely to be undiagnosed [59].

School census

School census data classifies disability according to a pupil’s primary type of need for state-funded schools. This information is discussed in Section 8.2.1 and displayed in Figure *17*. The most common primary type of need in Hackney primary schools are those of Speech, Language and Communication, in Hackney secondary schools are moderate learning difficulties and in Hackney special schools the most common type of need is Autistic Spectrum Disorder. For the state-funded primary school in City of London the most common primary type of need in January 2016 was specific learning difficulty.

The Key Hackney Voluntary Disability Register

For the 753 children and young people on the Hackney voluntary disability register 'The Key' only 126 (17%) have a disability registered and the coding used to categorise these do not follow the system of SEND used in education. Therefore this source will not be able to provide reliable data for discussion in this section.

Criminal justice system

Young people in contact with the criminal justice system often have complex needs in relation to health, care and the wider determinants of health (such as education, housing, deprivation). The number of young people in the youth justice system has been falling for the past 10 years. However, those who are discharged from custody have a 68% chance of reoffending within a year, which reflects the pattern of crime that may not be addressed within prison. [77]

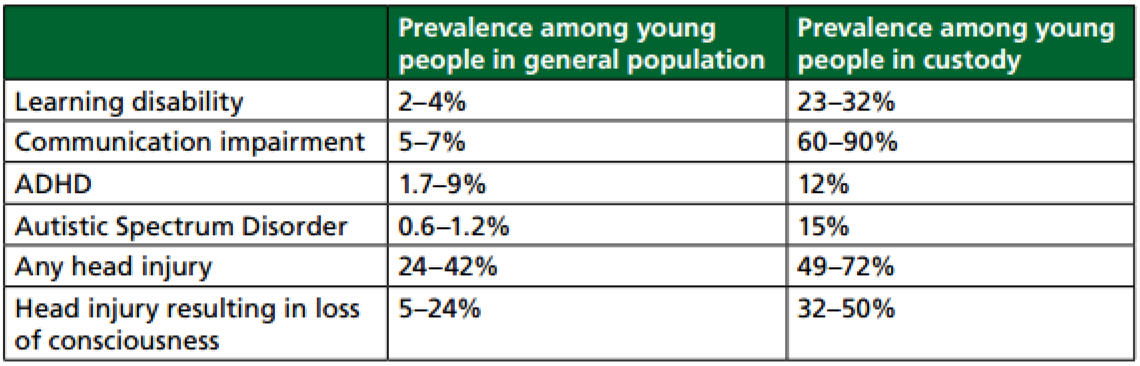
There is considerable evidence that the prisoner population have higher health needs than non-prisoners.[78] Adults in the criminal justice system display poor mental, emotional and physical health. 'Beyond youth custody' report that 11% of children in prison have attempted suicide. According to the same organisation, less than 1% of all children in England are in care, but looked after children make up 33% of boys and 61% of girls in custody. [77] [79]

The transition to adulthood (for young people engaged with local statutory services) has been highlighted as a period which can exacerbate offending behaviour, especially where services are poorly planned or unclear.

There is compelling evidence of the higher prevalence of neuro-disabilities and mental disorders in young people in custody (as shown by the table below). This evidence is acknowledged by the British Psychological Society (BPS), the House of Commons Justice Committee, Her Majesties Inspectorate (HMI) of Prisons and HMI Probations. Neuro-disabilties are defined by the BPS in the list below:

- Intellectual disabilities
- Specific learning difficulties
- Communication disorder
- Attention deficit hyperactivity disorder (ADHD)
- Autism spectrum disorders (ASD)
- Traumatic brain injury (TBI)
- Epilepsy
- Foetal alcohol syndrome.

Figure 28: Prevalence of disability among young people in custody



	Prevalence among young people in general population	Prevalence among young people in custody
Learning disability	2–4%	23–32%
Communication impairment	5–7%	60–90%
ADHD	1.7–9%	12%
Autistic Spectrum Disorder	0.6–1.2%	15%
Any head injury	24–42%	49–72%
Head injury resulting in loss of consciousness	5–24%	32–50%

Source: The treatment of young adults in the criminal justice system 2016 [77]

Mental health and criminal justice

A UK study in 2005 showed a third of young offenders had a mental health need. This was broken down as follows: almost a fifth of young offenders had problems with depression, while a tenth of young people reported a history of self-harm within the last month. Similar rates were found for young people suffering from anxiety and PTSD. Hyperactivity and psychotic-like symptoms were reported in 7% and 5% of young people, respectively. [78]

Learning disability and criminal justice

A person in the criminal justice system with a learning disability, or another condition that affects their ability to understand and communicate, is considerably more vulnerable to exploitation and bullying. They are often more suggestible and easily influenced by others and also more likely to be a victim of crime themselves. Without the necessary communication support a person with learning disabilities in the criminal justice system is put at a real disadvantage.

For those in prison under 18, one study found 23% to have an IQ score under 70, and 36% had scores between 70-79. The average IQ score of the general population, in the UK, is 100. [78]

The prison reform trust report a rate of dyslexia at around 30% which is generally agreed upon within prison-based studies. In addition, serious deficits in literacy and numeracy have been recorded in 60% of prisoners (defined by the Basic Skills Agency Initial Assessment as having a reading ability equivalent to or less than that of a 5-year old child).

People with severe learning disabilities are more likely to be known to social services and receive regular support in the community or a residential setting. Typically this group are less likely to offend. It is those people with mild or mild-to-moderate learning disabilities who are more likely to find themselves in the criminal justice system.

For those in prison under 18, one study found 23% to have an IQ score under 70, and 36% had scores between 70-79 (threshold for learning disability is generally under 70). However the low IQ scores may be due to the lack of/inconsistent education as opposed to any neurological deficits. [78]

Recommendations

The British Psychological Society call for:

- Wider recognition and understanding of neuro-disabilities in children and young people across health, social, education and justice agencies.
- Earlier assessment and intervention of neuro-disabilities in children and young people before coming into contact with the criminal justice system.
- Screening for neuro-disabilities in children and young people at earlier stages within the criminal justice process.
- Adoption of neuro-disability assessments when developing offender management plans to ensure appropriate neuro-rehabilitation is provided.

Methods of assessment of need may not reach a consensus, but some form of identification is nevertheless important if needs are to be addressed. More often than not, no systematic screening of learning disability or learning difficulty takes place at all in custodial settings, nor is available information (where it exists) routinely passed to establishments. [79] [77]

Research into Antisocial Behaviour Orders, for example (BIBIC 2005), found that people with learning disabilities or autistic spectrum disorders often did not understand the terms of the Order or why it was imposed. This makes compliance with such community-based penalties highly unlikely, which in turn increases the likelihood of eventual custody.

8.5 Key Points – Prevalence of Disability

KEY POINTS

- Estimates of disability vary dramatically from 3.0% of 0-18 year olds to 19.11% of 0-19 year olds.
- There is no single database or register that currently captures all the disabled children and young people in Hackney and the City of London.
- There are double the number of males compared to females on the Hackney voluntary disability register ‘The Key’.
- Children and young people who self-report to be White are under-represented in both state-funded special schools compared to the general Hackney population and those who report as Black are over-represented.
- The most common disabilities within schools vary depending on whether it is a state-funded primary, secondary or special school, and varies between Hackney and the City of London primary schools.
- Those from manual socio-economic family backgrounds are more likely to have a disability than those from a professional or managerial family background.
- There are likely to be a significant proportion of people in the youth justice system with a neuro-disability

9 Mental Health

It is estimated that one in ten children aged five to 16 have a clinically significant mental health problem. [78] It is also well-established that adult mental health problems often commence in childhood. Half of adult mental illness begins before the age of 15, with three-quarters (75%) beginning before the age of 18. [79] Of importance, for some conditions such as psychotic illness those who have symptoms at a young age, although more likely to have severe illness, often have a good response to treatment. [80] This emphasises the need for identifying mental health problems in children and young people so that appropriate evidence based treatment can be commenced as soon as possible. The Healthy Child Programme suggests that the school health review conducted on the transition to secondary school could aim to identify mental health issues to allow for early intervention. [81] The government has recognised and commented upon the value of mental health services for children and adolescents, such as in the document No Health Without Mental Health:

> "By promoting good mental health and intervening early, particularly in the crucial childhood and teenage years, we can help to prevent mental illness from developing and mitigate its effects when it does."[12]

Mental health is also recognised as a priority locally by City and Hackney CCG. [52]

A child or young person may be classified as having a disability on the basis of a mental health problem alone. A recent report by Public Health England identified mental health illness as a leading cause of health related disability in children and young people. [82] However for others, mental health problems are in addition to other health problems and physical or intellectual disabilities.

Individuals with learning disabilities and autism are at particular risk. International studies estimate that 40% of children and young people with learning disabilities are likely to have a diagnosable mental health problem. [83] The National Autistic Society reports that those with autism are also at a higher risk, with 70% of autistic children having a co-existing mental health problem. [84] Children with developmental disabilities are less likely to access mental health services, and when accessed are less likely to have their needs identified and addressed. For example, behaviour change as a symptom of depression may be incorrectly attributed to their disability, which is termed 'diagnostic overshadowing'. [85]

Physical health problems also increase the likelihood of mental health problems. Children with long-term health problems have 2-6 times higher risk of suffering from emotional or behavioural problems than their peers without chronic health conditions. [82] [86]

Children and young people with mental health problems are supported by Child and Adolescent Mental Health Services (CAMHS). CAMH services are divided nationally into four tiers as outlined in Figure 29. The lowest tier (Tier 1) can be provided by all professionals who support children and young people's health, education and social care needs. Figure 29 also displays the estimated percentage of the 0-16 year old population likely to require each tier of CAMHS services. As illustrated, over 1 in 10 children will

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[12] No Health Without Mental Health: A cross-government strategy (2011)

require Tier 1 support, whereas a very small proportion will require more intensive Tier 4 services.

Figure 29: Child and Adolescent Mental Health Services Tiers (0-17 year olds)

Tier	Services	Estimated need in 0-16 year olds
1	Practitioners across universal services who are not mental health specialists. Includes wellbeing promotion, advice and signposting (e.g. GPs, teachers, social workers).	15%
2	Child and Adolescent Mental Health practitioners working within community teams and primary care treating mild to moderate problems (e.g. counsellors working in GP surgeries).	7%
3	Multi-disciplinary services working in community or outpatient setting who care for CYP with more severe, complex and persistent conditions.	1.85%
4	Intensive community treatment services, day units and inpatient services for children who require intensive input.	0.075%

Source: Integrated Care Pathways for Mental Health [87] [88]

As children and young people are far more likely to attend secondary education than attend the GP or have a social worker, NICE has published guidance on how secondary education establishments can help improve the emotional wellbeing of young people. This would come under Tier 1 CAMHS services. This includes ensuring that young people have access to pastoral care as well as specialist services for emotional, social and behavioural problems. Training in promoting social and emotional wellbeing should be integrated into training for professionals within secondary education. [89]

9.1 Description of CAMHS services

CAMHS caters for children and young people aged 0-18 years old. City and Hackney CAMHS are divided into three main teams, with an in-house Clinical Service for children and families accessing Hackney Children and Young People's Services-. However, City and Hackney CAMHS operate a 'no wrong door' policy, therefore if a child or young person is referred to the inappropriate team internal referral will ensure that they reach the right service. The CAMHS referral pathway is included for reference as Appendix 1. Once a young person reaches 18, if they still require mental health services they are transferred to the care of the adult Mental Health team.

First Steps (Tier 2 service): This is an NHS Psychology service for those with difficulties affecting their behaviour, emotions and relationships. The team includes clinical psychologists, mental health nurses and assistant psychologists. [90] It is an early intervention service usually providing short-term support. Referrals can either be made by the individual, their family or a professional. The team does not work with those who are under the Children's Social Care team.

Specialist CAMHS (Tier 3 service): Specialist CAMHS caters to those with significant emotional, behavioural and mental health issues. The team includes psychiatrists, psychologists, psychotherapists and psychiatric social workers. [91] The team care for those whose needs are higher than the First Steps team and may need more long-term input.

CAMHS Disability (Tier 3 service): The Disability team specifically cater to children and young people who have a moderate to profound learning disability in combination with emotional, behavioural or mental health difficulties. The multi-disciplinary team includes psychiatrists, clinical psychologists, play specialists, systemic family therapists and psychotherapists. [92]

Hackney Children & Young People's Clinical Service: is an integrated and specialist Child and Adolescent Mental Health Services (CAMHS) for children accessing Children's Social Care Services, the CYPS Family Support Service, Young Hackney and Youth Offending Services. It works in partnership with the City and Hackney CAMHS Alliance and is accountable through the CYPS Emotional Health and Wellbeing Partnership Board

9.2 Estimated level of need

9.1.1 **Prevalence**

The Mental Health Foundation report 'Treating People Well' estimated the proportion of children aged 0 to 16 which would require support at each service tier, with figures ranging from approximately 1 per 1000 children needing tier 4 services to 150 per 1000 children requiring tier 1 services as shown in Figure 29 above. [88]

A national survey to establish prevalence rates was conducted by Green et al. in 2004. [78] By sampling from the Child Benefits Records 7,977 interviews were conducted. Children, parents and teachers were surveyed and found one in ten children and young people aged 5 to 16 had a diagnosed mental disorder. This rate of 10% of children suffering a clinically significant mental health problem has also been quoted in recent Public Health England reports. [82]

The prevalence of mental health disorders varies by condition, gender and age as discussed in the Inequalities section of this chapter. The overall estimated percentage of children with mental health disorders aged 5-16 is 9.6%. [78]

Another important finding of the survey was that approximately one in five children with a diagnosed disorder had more than one type of disorder. Therefore 1.9% of all children aged 5 to 19 had multiple disorders.

There is relatively little data regarding prevalence of mental health disorders in preschool children. However a literature review conducted by Egger et al of four studies found an estimated prevalence rate of any mental health disorder was 19.6% for those aged 2 to 5. [93] When applied to the local pre-school aged population we would estimate that 3,000 children aged 2 to 5 years have a mental health disorder in Hackney and 40 in the City of London. [94]

9.3.1 Service use

The Integrated Care Pathways for Mental Health estimates a total of 13,852 children and young people aged 0-16 (approximately 24%) would require CAMHS services in Hackney and the City of London as outlined in Figure 30 below.

Figure 30: Estimated number of children and young people aged 0-16 requiring CAMHS service for the year 2016.

	Percentage (%) of 0-16 year olds	Hackney	City of London
Tier 1	15%	8685	120
Tier 2	7%	4053	56
Tier 3	1.85%	1071	15
Tier 4	0.075%	43	1

Source: GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59] Integrated Care Pathways for Mental Health [87] [88]

9.3 Those known to local services

It is difficult to establish how many children are using CAMHS in its entirety. This is due to the fact that Tier 1 services are provided universally, by teachers, doctors and youth centres etc. There is no database gathering information on all those who utilise Tier 1 services as it is often on an ad hoc or informal basis. Unfortunately there is also no available data on the total numbers of children and young people utilising tier 2 services. This is secondary to the fact that some Tier 2 services are provided by schools, youth clubs and other general settings. [95] However, data is available for those accessing Tier 2 services provided by First Steps, and those accessing Tier 3 services via Specialist CAMHS and CAMHS Disability.

The total number of those accessing the three services mentioned above for the year 2015/2016 was 2,230.

9.4.1 Tier 2 Services data (First Steps)

For the 2015-2016 year a total of 1,252 children and young people (CYP) were referred and a total of 1,062 (85%) were accepted by the First Steps service.

9.4.2 Tier 3 Services Data (Specialist CAMHS and CAMHS Disability)

Specialist CAMHS

A total of 1,178 CYP were referred to Specialist CAMHS in 2015-2016. A total of 883 (75%) were accepted.

CAMHS Disability

In the year 2015-2016 a total of 328 children and young people were referred to the CAMHS Disability service. Of those 285 (87%) were accepted.

9.4 Unmet Need

Due to the fact that data is not available for those utilising all Tier 1,2 and 4 services, only unmet need for level 3 services can be commented upon.

It is estimated that 1.85% of 0-16 year olds require Tier 3 services. When applied to the Hackney and City of London 2016 populations this would equate to 1,086 children and young people.
There were 1,506 children and young people who accessed Tier 3 City and Hackney CAMHS services in 2015/16. This figure is higher than the estimated level of need. However it should be noted that the estimate only includes those up to age 16, whereas CAMHS is available to those aged up to 18, therefore the estimate is likely to under-represent the level of need.

9.5 Inequalities

Data regarding the gender and age of those utilising First Steps, Specialist CAMHS and CAMHS Disability for the year 2015/2016 is also available. Breakdown of ethnicity, deprivation and disability was not available.

9.6.1 Gender

Estimated rates from literature

Estimated rates of mental health problems differs depending on both gender and age as displayed in Figure 31. [78] Rates amongst boys was higher than girls for all mental disorders other than for emotional disorders, which are more common in girls across all ages.

Figure 31: Prevalence of mental disorders by age and sex as a percentage (%)

Type of Disorder	Percentage of children with each disorder								
	5 to 10 year olds			11 to 16 year olds			5-16 year olds		
	Boys	Girls	All	Boys	Girls	All	Boys	Girls	All
Emotional disorders	2.2%	2.5%	2.4%	4.0%	6.1%	5.0%	3.1%	4.3%	**3.7%**
Conduct Disorders	6.9%	2.8%	4.9%	8.1%	5.1%	6.6%	7.5%	3.9%	**5.8%**
Hyperkinetic disorders	2.7%	0.4%	1.6%	2.4%	0.4%	1.4%	2.6%	0.4%	**1.5%**
Less common disorders[13]	2.2%	0.4%	1.3%	1.6%	1.1%	1.4%	1.9%	0.8%	**1.3%**
Total all disorders	10.2%	5.1%	7.7%	12.6%	10.3%	11.5%	11.4%	7.8%	**9.6%**

Source: Mental health of children and young people in Great Britain, 2004. Green et al.

Figure 32below utilises the Green et al. prevalence rates to calculate estimates for the Hackney population. In total 2,854 boys aged 5 to 16 (11.4%) and 1,750 girls (7.8%) are estimated to have mental health disorders in Hackney.

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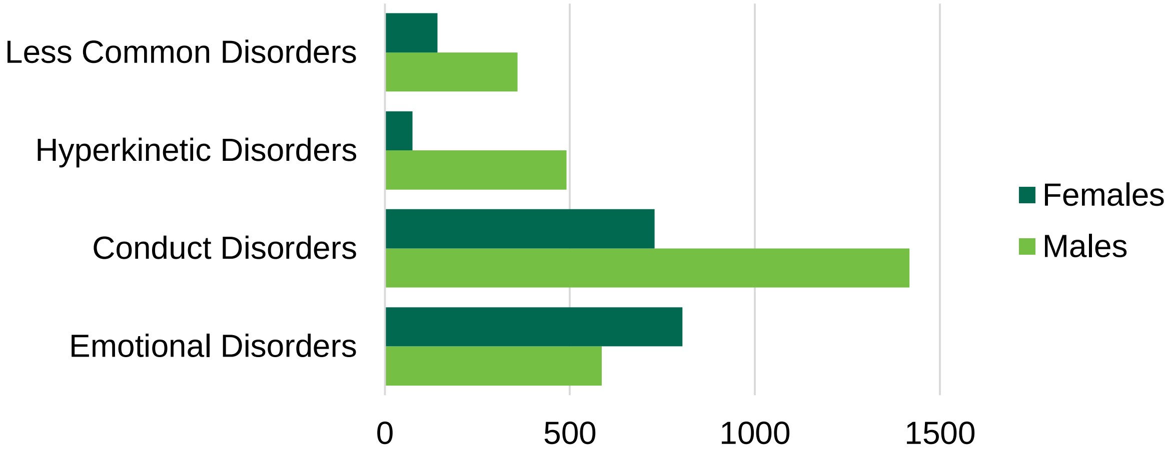
[13] Less common disorders include autistic spectrum disorder, eating disorders and selective mutism.

Figure 32: Gender specific estimated number of children aged 5 to 16 with mental health conditions in Hackney for 2016 population estimates



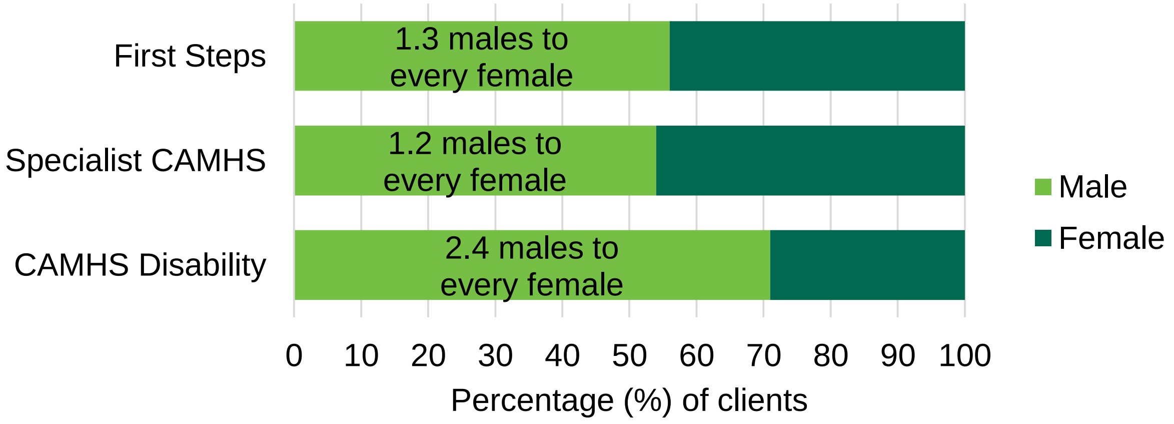
Source: GLA 2015 Round SHLAA-based Capped Household Size Model Population Projections (July 2016) [59] Green et al (2004). [78]

When applying the Green et al estimates to the 5-16 year old population of the City of London, there are estimated to be 19 boys and 19 girls with mental health problems. This would give a total estimate of 4,642 children and young people aged 5-16 with mental health problems in Hackney and the City of London.

Known to local CAMHS services

For all three services more males used the service than females as shown in Figure 33. This was most evident within CAMHS Disability service where 71% of those utilising their service were male. Gender differences were less pronounced in First Steps and Specialist CAMHS where 56% and 54% (respectively) of clients were male.

Figure 33: Percentage of children and young people of each gender utilising each service, as a percentage (%) of those accessing the service



Source: City and Hackney CCG 2015/2016 data

This gender split is in keeping with the estimated number of those with mental health problems by Green et al, where boys were estimated to be more likely than girls to have conduct, hyperkinetic and less common disorders. With regards to CAMHS disability the National Child and Maternal Health Intelligence network estimates males are more likely than females to have a disability. However the difference was 19.11% for males compared to 17.05% for females which due to the fact that total population gender split is almost equal would lead to an estimated gender split of 53% males to 47% females for those with disabilities, which does not account for the difference shown above for CAMHS Disability service.

9.6.2 **Age**

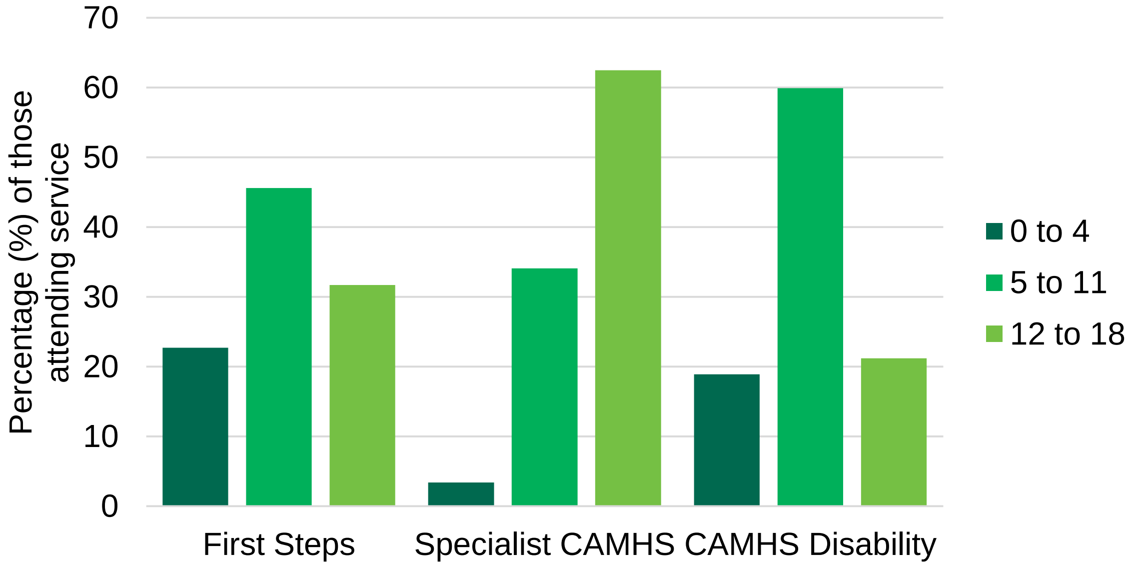
Estimated rates from literature

Variation in estimated rates of mental health problems for those of differing ages is outlined in the Gender section above (9.6.1).

Known to local CAMHS services

Age data of those utilising CAMHS services is grouped into 0-4, 5-11 and 12-18. As shown in Figure 34, the majority of those using First Steps and CAMHS Disability services were in the 5 to 11 year old age group, whereas those using the Specialist CAMHS service were mostly from the 12 to 18 age group. When analysing the number of clients seen for each age group across the three services, 13.8% were in the 0-4 age group, 43% in the 5-11 age group and 43.2% in the 12-18 age group.

Figure 34: Percentage of those utilising CAMHS service in each age group for the year 2015/2016



Source: City and Hackney CCG 2015/2016

It is not possible to compare this age breakdown directly to that of Egger et al and Green et al as the age groups differ significantly to those used for CAMHS data collection. For example, Egger et al percentage estimates are for those aged 2-5, whereas Green et al provides estimates for those aged 5-10 and 11-16.

9.6.3 **Ethnicity**

Although ethnicity was recorded for 83% of those using Specialist CAMHS and 90% of those utilising CAMHS Disability the breakdown of the recorded ethnicities was not available.

9.6.4 **Deprivation**

Data on postcode, area of residence or socio-economic group were not available.

9.6.5 **Disability**

Data on the disabilities of those utilising CAMHS Disability, or the number of those utilising any CAMHS service who had a disability was not available.

9.6 Key Points - Mental Health

KEY POINTS

- One in ten children aged 5 to 16 are likely to have a clinically significant mental health problem.
- Early identification and intervention for mental health problems is important to reduce the risk of crisis and requiring longer-term treatment.
- 75% of adult mental health illness begins before the age of 18.
- Mental health illness if a leading cause of disability in children and young people nationally.
- Those with disabilities and long term health problems are at a higher risk of mental health problems than their peers without disabilities long term illness.
- CAMHS services are divided into 4 tiers.
- It is estimated that 57% of children and young people requiring CAMHS services are not accessing mental health support.
- Of all those accessing First Steps, Specialist CAMHS and CAMHS Disability 60% are male and 40% are female.
- 14% of those accessing CAMHS services are aged 0-4, the remaining 86% are aged 5-18.

10 Autistic Spectrum Disorder

Autism is a neurodevelopmental disorder that is characterised by impairments in communication and socialisation, as well as repetitive or unusual behaviours. [96] The term 'Autistic Spectrum Disorder' (ASD) is used to encompass a range of conditions. Children with ASD can vary from being high-functioning with little need for additional support in day-to-day activities, to being low-functioning, non-verbal and requiring assistance with all activities of daily life.

It is important that we identify those with Autistic Spectrum Disorders to ensure that they receive evidence-based intervention when needed and that they and their families receive the support they require. Although diagnosis of ASD has improved, and the general public's knowledge of ASD has also grown there is still a lot of work that needs to be done for those with ASD. A Swedish study into the health and well-being of those with ASD was published earlier this year and suggested and found the average life expectancy of a person with ASD is 54 years old, compared to the average of 70 years for matched controls who did not have ASD. [1] Females with low-functioning ASD (classified in the study as having ASD and a co-existent Learning Difficulty) were at the highest risk, and were nine times more likely to die than a woman of the same age without ASD. As well as having higher rates of death from infections, cancer, and diseases of the circulatory and respiratory system, those with autism were 7.6 times more likely to die by suicide and 7.5 times more likely to die from epilepsy than those without Autistic Spectrum Disorder. This study emphasises that both the physical and mental health and well-being of those with ASD need to be considered.

Physical and mental health is not the only aspect of life that autism has an impact upon. Autistic pupils may require additional support within school, however only 37% of parents feel that their children are attending the kind of school that would best support them. [2] Seventy per cent of adults with autism report that they require more help from social services, and that receiving this assistance would help them feel less isolated. Employment is another area of inequality. Only 16% of adults with autism in the UK are in full-time paid employment. [2]

Guidelines regarding the diagnosis, management and support for children and young people with autism has been published by NICE. Management of the core features of autism includes recommendations regarding interactive play and vide-interaction feedback. Antipsychotic, antidepressant and anticonvulsant medication may be required for certain co-existing conditions but should not be used in the management of ASD. [97]

10.1 Diagnosis of Autistic Spectrum Disorder

For children and young people in City and Hackney there are four different pathways for assessment and diagnosis of Autism:

Age	Assessment
Under 5 years old	Assessed at Hackney Ark
Aged 5 to 13 year olds without a learning disability	Assessed at Hackney Ark
Aged 14 and over without a learning disability	Assessed by CAMHS, East London Foundation Trust
Aged 5 to 19 with a learning disability.	Assessed by the CAMHS Disability Team

More detail on these pathways are available on the City and Hackney CAMHS website. [98]

10.2 Estimated number of children with Autistic Spectrum Disorder

The Chief Medical Officer’s Report in 2010 estimated that at least 1% of children and young people nationally will have an Autistic Spectrum Disorder. [99]

A UK based study by Baron-Cohen et al estimated that the ratio of known cases of Autistic Spectrum Disorder: unknown cases of Autistic Spectrum Disorder to be 3:2. Therefore the estimated prevalence, including undiagnosed cases, would be 167 per 10,000 or 1.67%. [100]

Applying the estimated prevalence rate of 1% to the GLA SHLAA 2016 population estimates, this would result in an estimate of 960 children and young people aged below 25 in Hackney with ASD and 14 in the City of London. However, if the estimate were to include those children as yet undiagnosed the figure for Hackney would be 1,600 children and young people and 23 for the City of London.

10.3 Children with Autistic Spectrum Disorder known to local services

To try and establish which children are known to have Autistic Spectrum Disorder, this assessment utilises both City and Hackney CCG GP data and data from the Department for Education 2016 school census.

School census primary type of need data is only captured for those who are attending state funded primary, secondary and special schools. It will not account for those children who are attending independent or unregistered schools.

10.3.1 **School Census Data**

Schools report on a children with special educational needs and disabilities including their primary type of need. Autistic Spectrum Disorder is one primary type of need. Utilising the local authority SEND data, the total number of children in Hackney state-schools with Autistic Spectrum Disorder is 452.

The number of children with Autistic Spectrum Disorder attending the state-funded primary school in City of London is below 10 (unable to give exact figure due to confidentiality).

10.3.2 **City and Hackney CCG GP data**

A one-off search on 1/4/2016 of the medical records of those registered to City and Hackney CCG GP practices identified 808 children and young people aged 0-24 coded as having Autistic Spectrum Disorder. Those with ASD were identified by the Read Codes listed in Appendix 2.

10.4 Unmet Need

Utilising the estimate of 985 children and young people estimated to be diagnosed with ASD in Hackney and The City of London and comparing them to the school census data the number of children known to have autism (461 maximum), less than half are known to schools. However, school census data is likely to under-represent the true local number of those with ASD due to reporting methods (those with ASD as a secondary or tertiary need are not captured) and the lack of inclusion of independent and unregistered schools.

When comparing the estimated number of those with autism to those captured in City and Hackney CCG GP data, there are 177 (18%) fewer children and young people diagnosed with ASD than expected.

If utilising the estimate that includes those who are as yet undiagnosed the level of unmet need is even greater, with 815 (50%) fewer children and young people known to City and Hackney GPs than expected. By including the number who are estimated to have ASD but are as yet undiagnosed the figure is more likely to represent the actual level of local need.

10.5 Inequalities

10.5.1 Gender

Literature

There is a well-documented gender difference in prevalence of autism. However, the ratio of males to females with autism varies across studies from 2:1 to 16:1. In 2011, Fombonne et al conducted a research review of various papers and found a mean ratio of 5.5 males to each 1 female diagnosed with autism. [101] Lorna Wing found that for those with high-functioning autism (such as Asperger's) the male female ratio was 15:1, whereas for those with both autism and a learning disability the ratio was 2:1. [102].

Although it could be argued that these gender ratios suggest that females are less likely to develop autism, research suggests that females with autism may present differently and therefore not be identified using standard diagnostic tools. [103] Another possible explanation for the gender difference is that females may be better able to mask symptoms due to having better social skills than males.

School census SEND data

Gender data is not available for school census SEND data.

City and Hackney CCG GP data

Of the 808 children and young people aged below 25 coded as having ASD on their GP records 533 were male (66%), 276 were female (34%) This provides a gender ratio of approximately 2 males for each 1 female diagnosed with ASD.

10.5.2 Age

School census SEND data

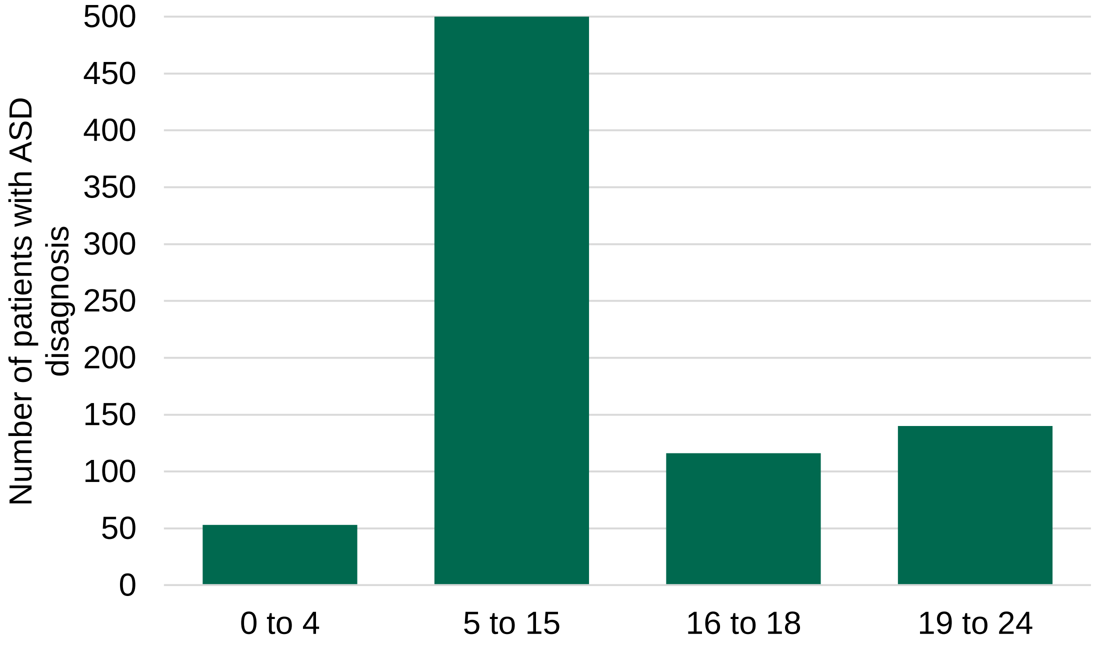
Of the 452 pupils attending Hackney state-funded schools identified as having Autistic Spectrum Disorder on the school census 221 attend mainstream primary schools, 98 attend mainstream secondary schools and 133 attend special schools. It is not possible to extract the ages of those attending the special schools.

Of those who are not attending the special schools 69% are attending primary school and are therefore aged 4-11, and 31% are attending secondary school and are aged 1-18.
All those identified on the school census as having ASD in City of London are attending the state-funded primary school and are therefore aged 4-11.

City and Hackney CCG GP data

Of the 808 patients coded on GP records as having ASD the majority were aged between 5 and 15 as shown in Figure 35. As expected the smallest proportion of patients are aged 0 to 4, where the behaviours linked to ASD are less likely to be as evident. Of note the age groupings utilised in this data differ from those used in other areas of this document.

Figure 35: Breakdown of number of those with diagnosis of ASD on GP records for each age group.



Source: City and Hackney CCG GP data (2016)

A total of 1,042 patients registered at City and Hackney GPs were coded as having an ASD. Therefore those aged 0 to 24 encompass three-quarters of the total Hackney ASD population.

10.5.3 Ethnicity

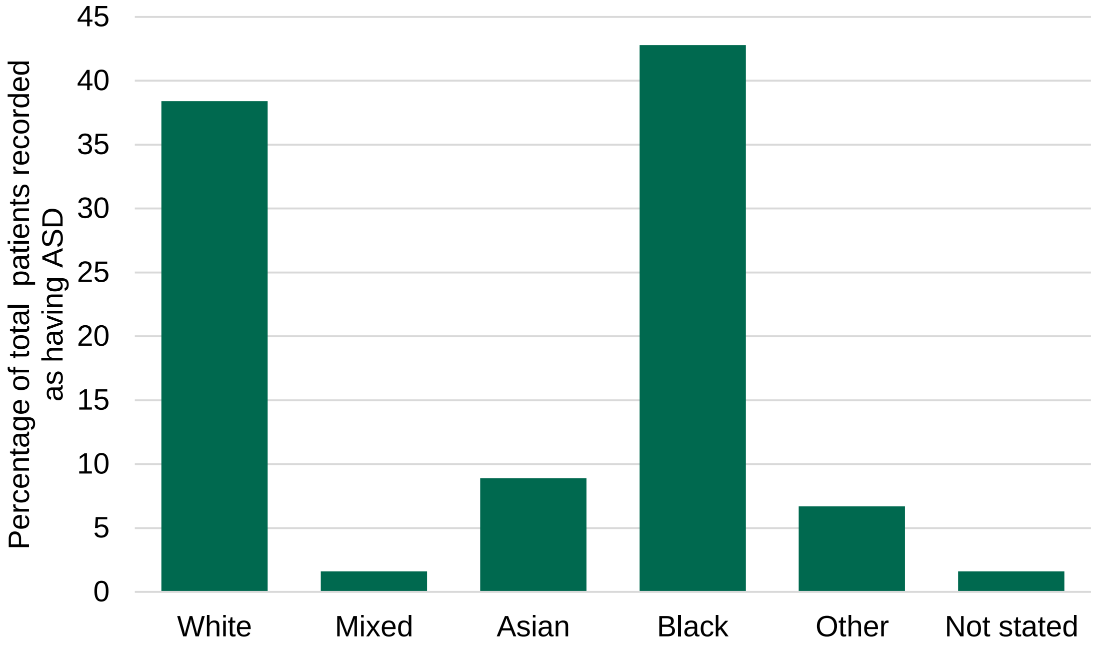
School census SEND data

Ethnicity data for those who have been classified as having ASD as their primary type of need on the school census is not available.

City and Hackney CCG GP data

Of the total of 1042 patients (all ages) recorded as having a diagnosis of ASD, the majority were Black, with the percentage who self-classified as white being second, as shown in Figure 36. Of note, this ethnicity data refers to the total all age population recorded as having an ASD so it is not possible to comment on the ethnic breakdown of patients aged 0 to 24 with ASD specifically.

Figure 36: Percentage of total number of patients (all ages) recorded as having ASD registered at City and Hackney GPs for each ethnicity



Source: City and Hackney CCG GP data (2016)

10.5.4 **Deprivation**

More specific data than the local authority of the school attended is not available for the school census, therefore it is not possible to comment on deprivation.

10.5.5 **Disability**

School census SEND data

As mentioned above, the school census only captures a pupil’s primary type of need so those with Autistic Spectrum Disorder and a coexisting cause for having Special Educational Needs or Disability this will not be recorded.

City and Hackney CCG GP data

Of the 808 children and young people aged 0 to 24 registered at City and Hackney GPs with ASD, 85 also had a diagnosis of a Learning Disability (all severities). Therefore 10.5% also had a co-existing Learning Disability. Data regarding other co-morbidities was not available.

10.6 Key Points - Autistic Spectrum Disorder

KEY POINTS

- Those with Autistic Spectrum Disorders (ASD) have a lower life expectancy than peers without ASD.
- Only 16% of adults with ASD in the UK are in full-time paid employment.
- In Hackney and the City of London diagnosis is made at Hackney Ark or by CAMHS.
- There are estimated to be 1,623 people aged under 25 with ASD in Hackney and 16 in the City of London (including those as yet undiagnosed).
- Research suggests that ASD is more common in males than females, however this may be due to presentation differing between genders.
- NICE has published guidelines regarding the diagnosis and management of autism in children and young people, and adults.

11 Obesity

For further information regarding rates of childhood obesity in the general Hackney and City of London population please see the 0-5 and 5-19 year old Health Needs Assessments.

When combining the results of the National Child Measurement Programme and a local Charedi pilot survey, 75% of reception aged children in Hackney and the City of London are of a healthy weight, 13% are overweight and 11% are obese. However, the National Child Measurement Programme does not include special schools. Children who attend mainstream schools but are unable to stand unaided on the weighing scales (such as children in wheelchairs) are also excluded from the data.

11.1 Evidence from literature

Obesity has been identified as a key health priority by City and Hackney CCG. [52] A report by Public Health England identified that disabled children and young people are more likely than their peers without disabilities to be obese, and the likelihood of being obese increases with age. [104]

In fact those with a limiting long-term illness[14] were 35% more likely to be obese than those without. Due to higher rates of obesity, children with disabilities are therefore at higher risk of obesity-related health problems such as type 2 diabetes cardiovascular disease and musculoskeletal problems. These children and young people are also at risk of their obesity being under-managed due to focus being placed on their disability, rather than their general health.

Certain studies have looked at the prevalence of disability in children with specific disabilities. For example, a recent American study identified that children with Autistic Spectrum Disorder were more likely than their peers without ASD to be obese, at 23.1% compared to 14.1% respectively. [105] Spina bifida is a condition which affects the spinal cord and cause a varying degree of mobility problems. American research identified that obesity rates in children with spina bifida were 18.6% compared to 13% in a similar population without disabilities. [104]

The reason for increased levels of obesity in the disabled population is multi-factorial. Some of these factors have been outlined in Figure 37 below. This list is not exhaustive.

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[14] Limiting long-term illness referred to following questions: Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time? (Yes /No) Does this illness or disability/do any of these illnesses or disabilities limit your activities in any way? (Yes/No). If they answered yes to both questions they were identified as having a limiting long-term illness.

Figure 37: Risk factors that increase that may contribute to obesity in disabled children.

Risk Factor	How this leads to obesity
Medication	Medications such as anti-psychotics can lead to weight gain as a side effect.
Prader-Willi syndrome	This is a genetic disorder which causes hunger which is not satiated by eating, leading to eating large amounts of food.
Disabilities affecting mobility	Disabilities leading to musculoskeletal problems can limit physical activity.
Autism	Children with autism may have sensory issues with certain textures, smells or flavours of food which can lead to a restricted diet.
Social isolation	Lack of social participation can lead to over-eating in children with disabilities.
Accessibility	Lack of exercise and recreation activities accessible to those with disabilities can reduce physical activity contributing to weight gain.
Pain	Pain may make a child reluctant or unable to participate in any physical activity.

Source: Obesity and disability: Children and young people. Public Health England (2013)

Public Health England published a report for commissioners outlining reasonable measures to undertake to help tackle obesity in those with learning disabilities. [106] Although the document is not specifically relating to children and young people the strategies are still relevant in this population. The adjustments outlined include:

- *Raising awareness of excess weight with people with learning disabilities, their family and carers.* Research suggest that the main barrier to physical activity for those with LDs are a lack of understanding of its benefits.
- *Annual health checks.* Health checks are an opportunity to review an individual's health in a holistic manner including advice on diet and exercise, managing obesity related conditions such as Type 2 diabetes and reviewing medication that may lead to weight gain.
- *Including family and care staff.* Supplying families and carers with information on healthy eating and exercise to become healthy role models.
- *Ensuring mainstream healthy weight programmes are accessible.* Accessible information and resources are required as mainstream health promotion resources often require a certain level of literacy skills.
- *Environmental and social factors*. Ensuring that individuals are supported regarding finances and transport required to engage in physical activity can play a large role.

11.2 Estimated level of need

As discussed above children with a limiting long-term illness are 35% more likely to be obese than their peers without a limiting long-term illness.

Therefore, rather than the estimated rate across Hackney and the City of London of 11% of children being obese [107], for those with a limiting long-term illness or disability we would estimate that 15% would be obese.
When applying this to the estimated number of children and young people with disabilities in City of London and Hackney (15,366), we would estimate that there are 2,304 children and young people with disabilities aged 0-25 in City and Hackney who are obese.

11.3 Those known to local services

11.3.1 School Nurse Special School data

School nurses currently collect data on the height and weight of children within the state-funded special schools in Hackney. Unfortunately, data was not available in time for inclusion within this Needs Assessment.

11.3.2 Local weight management programme data

Healthy Lifestyles

The Healthy Lifestyles programmes consist of 6 programmes in total:

- Healthy Lifestyles (7-13 year olds)
- Healthy Living (13-19 year olds)
- OJ Healthy Lifestyles (7-13 year olds from the Charedi community)- Girls programme and boys programme
- OJ Step by Step (12-18 year olds with disabilities from the Charedi community)- Girls programme and boys programme

All those attending Step-by Step have a disability.
The total number of children and young people attending Step-by-Step in 2015/16 was 80.

Lifestyle Eat-well Activity Positivity (LEAP)

LEAP is a multi-disciplinary weight management service for children and young people in Hackney and the City of London. Although eligibility is usually for those whose BMI is above the 98th centile, for those with medical co-morbidities, psychosocial dysfunction or complex needs (e.g. learning disabilities) those with a BMI of above the 91st centile are eligible.

Unfortunately data regarding the proportion of attendees utilising LEAP with a disability was not available at time of publication.

11.4 Unmet need

It is not possible to quantify unmet need as there only data on those known to one local services at present.

11.5 Inequalities

11.5.1 Age

Although all those attending Step-by-Step are aged 12 to 18, the exact age breakdown of attendees was not available.

11.5.2 Gender

Of the 80 disabled young people attending Step-by-Step, 40 were female and 40 were male.

11.5.3 Ethnicity

All those attending Step-by Step were from the Charedi community.

11.5.4 Deprivation

Deprivation data was not available.

11.5.5 Disability

Data on disability of those attending Step-by Step was not available.

11.6 Key Points- Obesity

KEY POINTS

- Children and young people with disabilities are estimated to be 35% more likely to be obese than their peers without disabilities.
- The cause of this increased risk of obesity is multi-factorial and includes medication, sensory issues regarding food and social isolation.
- NICE has outlined measures that should be put in place by local authorities to increase accessibility to weight management services.

12 Oral Health

‘**Poor oral health impacts children and families’ health and wellbeing. Oral health is an integral part of overall health; when children are not healthy, this affects their ability to learn, thrive and develop.’** [108]

Oral health is hugely important as teeth are involved in eating, speech and facial expressions. If oral health is poor this can lead to pain, eating difficulties and speech difficulties. The most common oral disease affecting children and young people in England is tooth decay. Tooth decay is a common cause of hospital admissions in children, however tooth decay itself can be prevented. Studies have shown that disabled children are more prone to tooth decay and other oral health problems as outlined below.

NICE published guidelines in 2014 identifying those with disabilities as being one of the population groups particularly vulnerable to poor oral health, encouraging local authorities and partners to particularly focus on these vulnerable groups. [109]

In line with these guidelines a new oral health services specification was implemented in 2016 in Hackney. This involved both fluoride varnishing in state-maintained schools and Charedi schools as well as a supervised tooth-brushing programme in state-maintained special schools.

12.1 Evidence from Literature

Research has shown that children with chronic conditions have poorer oral health than those without. [110]

There are multiple factors that increase the risk of oral health problems for disabled children and those with chronic conditions, as outlined in

Figure 38 below.

Figure 38: Factors increasing the risk of oral health problems in disabled children and young people

Risk Factor	Explanation
Medication	Some medications (especially liquid preparations) contain sugar which can lead to tooth decay
Dry mouth	Some medications (e.g. proton pump inhibitors, opiates etc.) can cause a dry mouth which can increase the risk of decay.
Tolerance to tooth brushing	Some children may not tolerate having a toothbrush in their mouth or may have a strong gag reflex making brushing difficult.
Behavioural	They may have a preference to sweet food/drink, which can contribute to decay.
Food pouching	Some children may keep food in their mouths for prolonged periods or retain small amounts of food around their teeth.
Gastric Reflux	Some children will have gastric reflux, and the stomach acid may lead to damage of the tooth enamel.

Source: Teeth matter! Caring for your children's teeth. Public Health Agency. 2010. [111]

However, there are ways to reduce the risk of tooth decay and subsequent dental caries. Fluoride is a naturally occurring mineral that can help prevent tooth decay. Fluoride can be added to toothpastes and applied as a varnish in the form of a gel over teeth. A Cochrane review was conducted into fluoride varnishing in 2013. [112] 22 trials conducted between 1975 and 2012 covering 12,455 children were reviewed comparing fluoride varnishing to a placebo or no treatment. The review found that fluoride varnishing led to a 37% reduction in dental caries, missing teeth and fillings in first/baby teeth. The studies researching the efficacy in permanent adult teeth found that young people who had fluoride varnishing had a 43% reduction in cavities, fillings and missing teeth. As part of Public Health England's evidence-based toolkit, fluoride varnish is recommended twice a year. [113]

12.2 Estimated level of need

The first national survey of oral health in children with disabilities was conducted in 2014. The report 'Dental public health epidemiology programme, oral health survey of children in special support schools' was published in 2015. [114] The prevalence of tooth decay across those surveyed in special schools in England was lower than that of mainstream schools, at 22% and 28% respectively. However, those with a substantial amount of plaque was double those in mainstream schools, with 4% of 5 year olds in special schools affected compared to 2% in mainstream schools. They were also twice as likely to have had one or more teeth removed compared to peers in mainstream schools. Unfortunately the number of children examined in Hackney was below 20 and therefore too small to provide population estimates for the community and there were zero children included in the survey from City of London. [115] The identified prevalence of decay and untreated decay is displayed in Figure 39.

Figure 39: Percentage of 5 and 12 year olds attending special support schools with decay experience and untreated decay grouped by disability type.

	5 year olds		12 year olds	
Disability	% with decay experience	% with untreated decay	% with decay experience	% with untreated decay
All disabilities	22.5	17.2	29.2	15.4

Source: Oral health survey of five-year-old and 12-year-old children attending special support schools 2014. Public Health England. 2015 [114]

Utilising the all disabilities rates to calculate estimated level of need is not possible as rates are only available for 5 and 12 year olds.

12.3 Those known to local services

12.3.1 City and Hackney CCG data

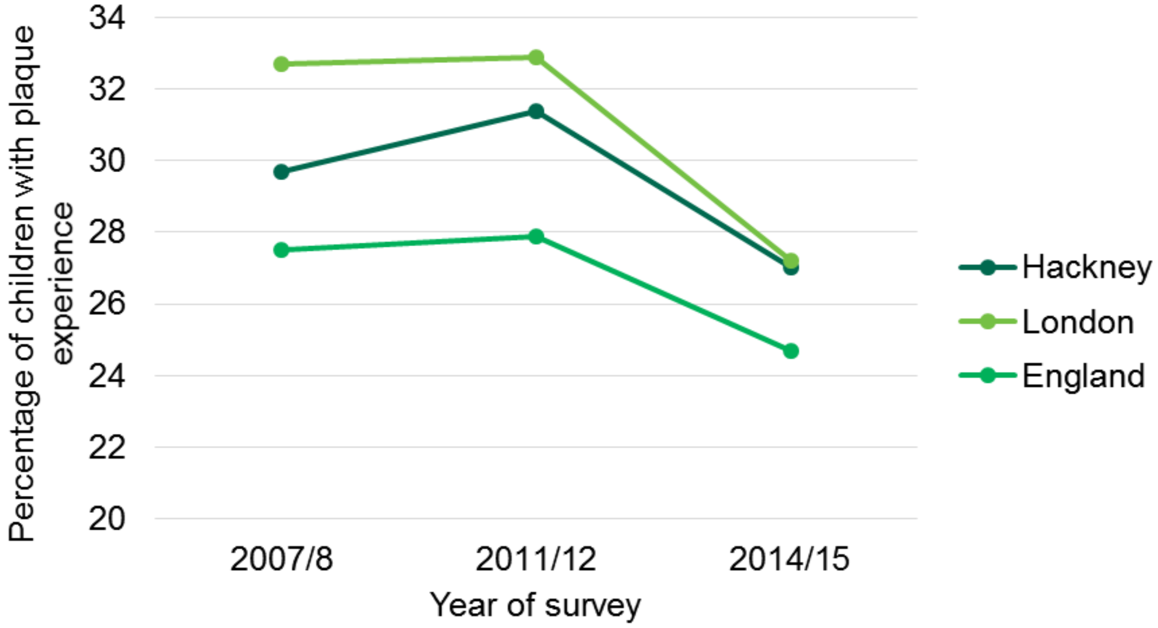
In Hackney and the City oral health is a significant problem. Only 31.8% of children within City and Hackney CCG were seen by an NHS dentist in 12 months (1st April 2015 to 31st March 2016). This was just over half the average percentage of children in England of 57.9%. [116] This data includes both those with and without disabilities

12.3.2 Dental Public Health Intelligence Programme- National survey of five year old children

The Dental Public Health Intelligence Programme collects data regarding the oral health needs of local populations. They analyse and disseminate the data. Different groups are surveyed and of particular relevance to this Needs Assessment the oral health needs of 5 year old children and of those attending special (non-residential) schools is also surveyed.

The latest survey of 5 year old children was conducted in 2014/15.
The results showed that showed that 27% of 5 year old children in Hackney had decay experience. [117] This data is level with that of London however is 2% higher than that of the average across England (see Figure 40 below).

Figure 40 Percentage of five year old children who have plaque experience across Hackney, London and England.



Source: Lower Tier LA, PHE Centre and regional results tables 2015. 2014/15 Survey of 5 year old children. Public Health England [117]

However this is an improvement from the previous survey in 2011/12 where the percentage of 5 year olds in Hackney with decay experience was 31.7%.
Dental abscesses are collections of pus as a result of a tooth infection. These can be due to deep cavities and can be used as a measure of poor dental health.
The rate of dental abscesses across 5 year olds in Hackney in 2014/15 was 2.1%. This was just below the 2.2% average across London but higher than the average across England of 1.7%. Unfortunately data from the 2014/15 survey provided too small a sample size for City of London to be included.

12.3.3 Pilot Charedi population survey

As the Dental Public Health national surveys above only capture those attending state-schools, the significant number of children attending independent Orthodox Jewish schools are not included. Therefore to measure local need, in 2015 (using sampling and methodology similar to that used in the National Dental Public Health epidemiology programme), the oral health of five-year old children from the Charedi population was measured. Eight independent Charedi schools were included, four for boys and four girls schools. In total 120 children were examined and 70 parents/carers returned questionnaires regarding oral health.

Over half of the Charedi children in Hackney examined had dental decay (58.4%) compared to just over a quarter (27%) across Hackney and London. The mean number of decayed, missing and filled teeth (dmft) was almost three times higher in the Orthodox Jewish pupils at 2.38 than those attending state-funded schools (mean dmft of 0.8).
The questionnaire responses found that only 20% of the five year old children attending independent Orthodox Jewish schools had their teeth brushed twice a day, compared to 82% across England as a whole. The results of the survey are currently pending publication.

12.3.4 Community Dental Service- St Leonard's Primary Care Centre

The City and Hackney Community Dental Health service provides dental care for those with a variety of needs who may not be able to access mainstream dental services. Those accessing the service include those with:

- Blood borne viruses
- Homeless/temporary housing
- Learning disabilities
- Substance/alcohol dependency
- Physically disabled
- Mental health problems
- Phobic (of dentists)
- Housebound
- Medically compromised
- Behaviour problems
- Child with complex social problems
- Vulnerable adult
- Travellers

In the year 2015/16 a total of 1,063 children and young people aged 0-25 utilised the service.

The Senior Dental Officer from the service advised that all those classified as learning disabilities, physically disabled, mental health problems, housebound, medically compromised and behaviour problems, have a disability.

Using the numbers coded as having these needs, 483 disabled children and young people aged 0-25 accessed the service in 2015//16.

12.4 Unmet need

As there is no available estimates of prevalence of tooth decay and tooth extraction across children and young people aged 0-25 or 0-18 with disabilities, it was not possible to calculate estimated level of need. Therefore it is not possible to calculate unmet need.

12.5 Inequalities

12.5.1 Gender

Community Dental Service

Of the 1,063 people (aged 0-25) who utilised the specialist Community Dental Service in 2015/16, 519 (49%) were female and 51% were male. This reflects a similar

12.5.2 Age

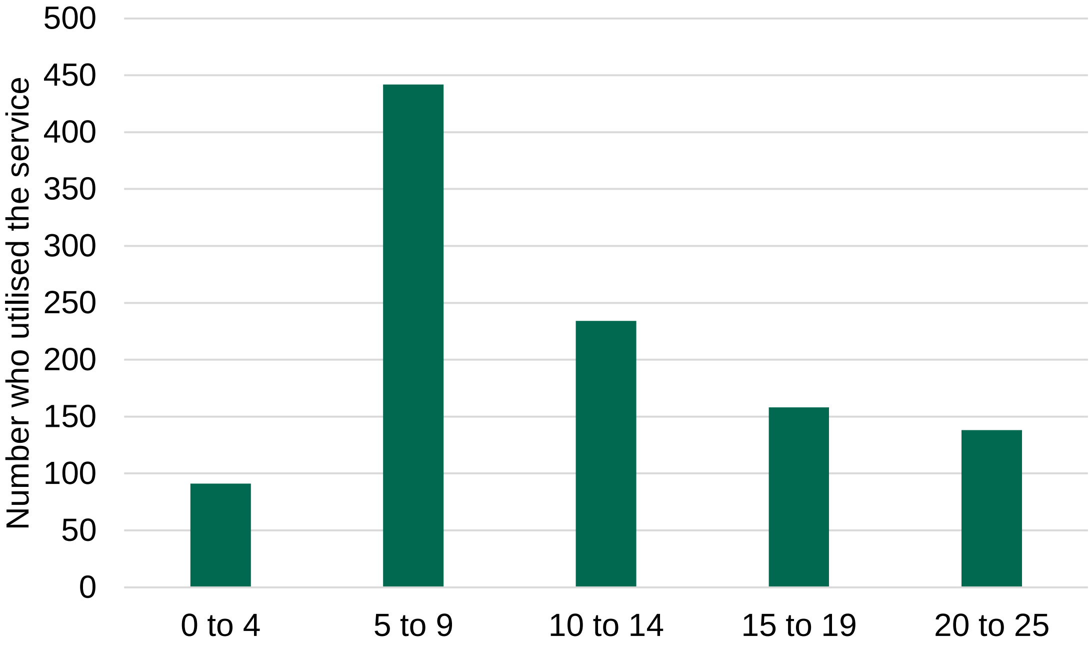
Dental Public Health surveys

Levels of both tooth decay and tooth extraction were higher in 12 year olds compared to 5 year olds surveyed in the Dental public health epidemiology programme, oral health survey of children in special support schools as displayed in Figure 39.

Community Dental Service

As shown below in Figure 41, the majority of those aged 0-25 accessing the service were in the 5 to 9 year old age bracket.

Figure 41: Age breakdown of those aged 0-25 accessing the Community Dental Service in 2015/16



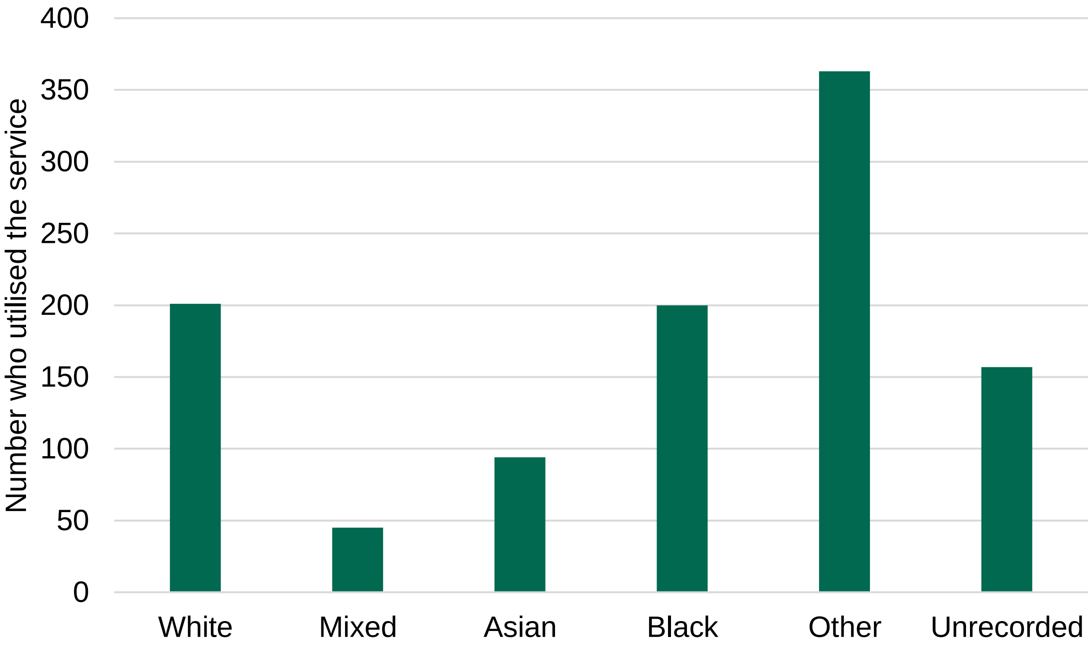
Source: Community Dental Service (2015/16)

12.5.3 Ethnicity

Community Dental Service

Of the 1,063 0-25 year olds who accessed the service 15% declined to disclose their ethnicity. Of the remaining 906 individuals, the majority self-reported their ethnicity as 'Any other ethnic group' as shown in Figure 42 below. The next largest ethnic groups were White and Black which made up 19% each.

Figure 42: Ethnicity of those aged 0-25 accessing the Community Dental Service in 2015/16



Source: Community Dental Service 2015/16

12.5.4 Deprivation

Postcode or local area of residence data was not available, therefore it is not possible to comment on deprivation.

12.5.5 Disability

Public Dental Health surveys

The Public Dental Health survey of special schools categorised children by type of disability. Measures of poor oral health did not show a strong difference between different types of disability for children aged 5. However in the 12 year old children, those with disabilities affecting socialising and behaviour were found to have higher levels of decay and untreated decay compared to those with other disabilities as shown in

Figure 43 below.

Figure 43: Percentage of 5 and 12 year olds attending special support schools with decay experience and untreated decay grouped by disability type.

	5 year olds		12 year olds	
Disability	% with decay experience	% with untreated decay	% with decay experience	% with untreated decay
Autistic Spectrum Disorder	25.3	17.8	25.7	14.3
Behavioural, emotional and social difficulty	27.6	24.1	41.5	25.6
Hearing or visual impairment	19.2	15.4	29.1	10.9
Specific learning disability	26.3	15.8	27.3	6.1
Moderate learning disability	25.1	22.9	30.1	16.2
Severe learning disability	20.5	15.6	27.8	15.9
Profound and multiple learning disability	20.5	14.6	23.1	8.7
Physical disability	18.6	15.3	20.0	11.7
Speech language and communication impairment	21.4	12.5	24.1	13.8
Other including ADHD, multi-sensory impairment	25.4	21.1	33.6	15.4
All disabilities	22.5	17.2	29.2	15.4

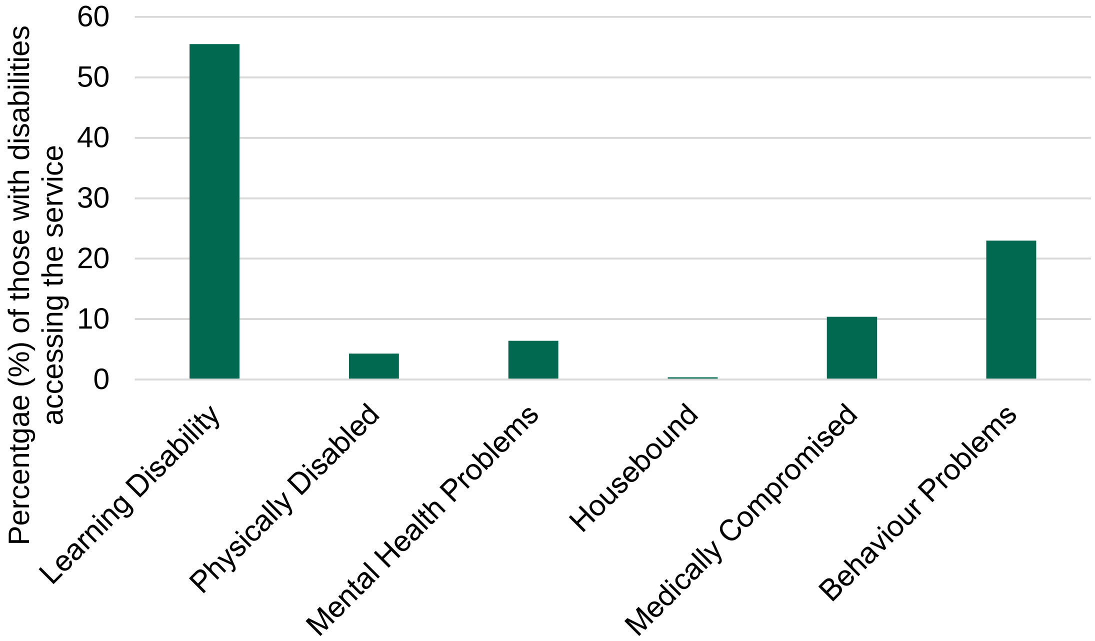
Source: Oral health survey of five-year-old and 12-year-old children attending special support schools 2014. Public Health England. 2015 [114]

Community Dental Service

Each individual attending the Community Dental Service are coded according to which need led to them requiring to access the service. The code is based on a subjective judgement by the dentist whom they see. Although multiple codes can be used, their primary code is that which is deemed the most significant. If an individual has a Learning Disability and a blood borne virus for example, they will be coded as Learning Disability.

The breakdown of the codes of those aged 0-25 with disabilities (483 in 2015/16) is displayed below in Figure 44. As shown, over half of those with a disability accessing the service have a learning disability.

Figure 44: Breakdown of primary need of those with disabilities accessing the Community Dental Service (age 0-25)



Source: Community Dental Service (2015/16)

12.6 Key Points - Oral Health

KEY POINTS

- Disabled children and young people are identified as being particularly vulnerable to oral health problems.
- Tooth decay and oral health problems can lead to issues with eating, speech and communication via facial expressions as well as causing possible pain and infection.
- Tooth decay is entirely preventable and interventions such as fluoride varnishing can greatly reduce levels of tooth decay.
- The prevalence of tooth decay in five-year olds from the Charedi community is over double that of Hackney average, with only 20% brushing twice a day.
- Rates of tooth decay within special schools nationally varies for different disabilities.

13 Respiratory Health

Respiratory health refers to the lungs and breathing. Some respiratory conditions can be defined as a disability is they meet the definition supplied in the Equality Act. For example, the ability to carry out normal daily activities may be impeded by the breathlessness and decreased exercise tolerance caused by cystic fibrosis or brittle asthma.

The most common non-communicable (non-infectious) respiratory condition is asthma. [118] Asthma, due to its prevalence can be a comorbidity for children and young people with disabilities or may qualify as a disability in its own right if symptoms are severe.

13.1 Asthma

Asthma is a respiratory condition that is characterised by variable airflow obstruction with the presence of symptoms of wheeze, breathlessness, chest tightness and cough. [119] There are many risk factors including a family history of asthma or related allergic conditions, being born premature or being born at a low birth weight. There is no single test to prove asthma, a diagnosis is often based on a combination of history of symptoms and clinical assessments and tests. Symptoms often start in childhood, and although some children eventually grow out of asthma, for others it continues into adulthood. There is no cure for asthma, however inhalers and medication can be used to help control symptoms and ease any attacks that may occur.

13.2 Estimated Asthma Prevalence

The 2010 Health Survey for England provided child and young people active asthma estimates of 1,100 per 10,000 boys and 800 per 10,000 girls. [120]

A meta-analysis of studies into asthma prevalence in 2007 concluded that prior to puberty prevalence is higher in males, whereas after puberty it is females who have higher rates of asthma. [121]

13.3 Those with Asthma known to local services

On the 1st of April 2015 a search of the database of those registered at City and Hackney CCG general practices was conducted to identify the number of people with active asthma. Active asthma was defined as having a received an asthma prescription within the last 12 months to exclude those who no longer had symptoms. A total of 3,210 children and young people aged 0-24 are known to have active asthma.

13.4 Unmet Need

Although the prevalence rates in Hackney and the City follow the established pattern of being higher in males prior to puberty and higher in females following puberty, the rates are lower than the national average for both genders. The rate in Hackney and the City is less than half the national average for those aged 0 to 24, with 417 per 10,000 males and 319 per 10,000 females identified as having acute asthma.

There is no reason to believe that Hackney and the City should have lower rates of asthma than national estimates, particularly as London as a whole has high levels of air pollution, exceeding the WHO guideline values of particulate matter. [122] The Aphekom study suggested that 15-30% of new cases of asthma in European children could be secondary to living near busy roads due to air pollution, therefore we would expect that rates of asthma in our population would be equal to or higher than the national average. [3]

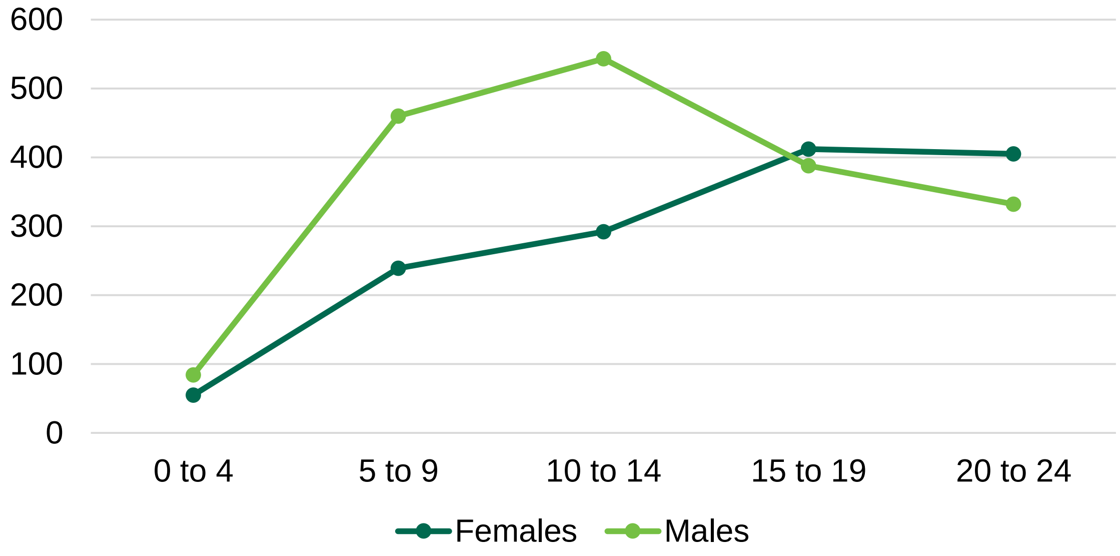
It is unclear whether this difference in national estimates and rates in Hackney and the City are due to genuinely lower rates or whether under-diagnosis plays a role.

13.5 Inequalities

13.5.1 Gender

Asthma prevalence varies by gender at all ages as displayed in Figure 45 below. The gender difference is largest in the 10-14 year old group where males outnumber females. However for all older age groups (15-19 to 90+), there are more females than males identified as having active asthma.

Figure 45 Number of males and females with active asthma on the 1st of April 2015 registered at City and Hackney CCG General Practices

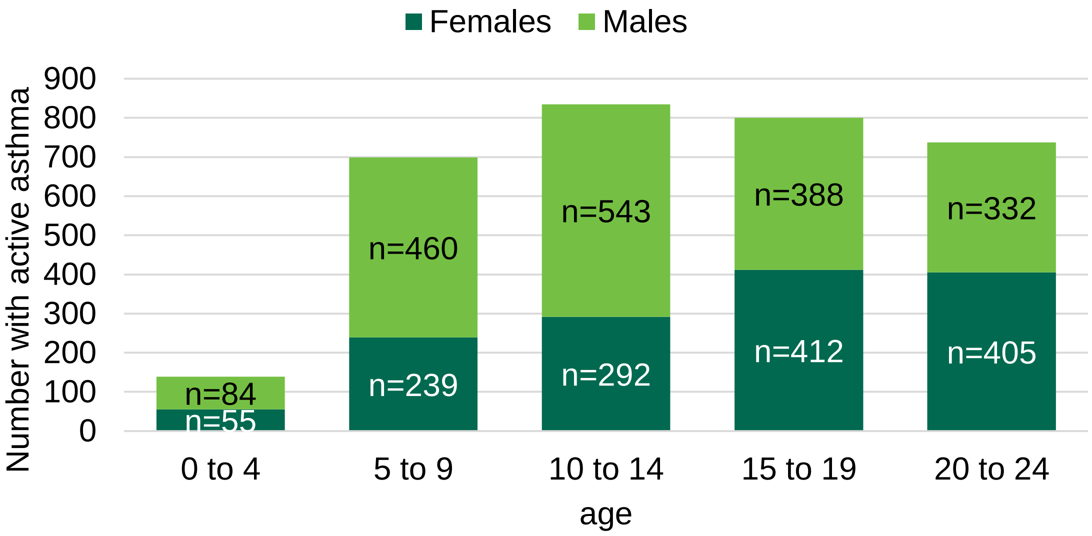


Source: City and Hackney CCG. Data collected 1st April 2015.

13.5.2 Age

Rates of asthma vary by age as displayed in Figure 45 below. The highest rate is in 10 to 14 year olds. The lowest rate is in 0 to 4 year olds. This is due to the fact that asthma is difficult to diagnose in those below 5 years of age as symptoms can mimic conditions such as viral wheeze.

Figure 46: Number of males and females with active asthma on the 1st of April 2015 registered at City and Hackney CCG General Practices



Source: City and Hackney CCG. Data collected 1st April 2015.

13.5.3 Ethnicity

Ethnicity specific data is not available.

13.5.4 Deprivation

Data regarding deprivation is not available.

13.5.5 Disability

Data regarding levels of asthma in disabled children is not available.

13.6 Key Points - Respiratory Health

KEY POINTS

- Asthma is the most common non-communicable respiratory condition.
- It is estimated that 11% of boys and 8% of girls have asthma.
- Research estimates that 15-30% of new asthma cases could be secondary to living in areas with high air pollution.
- Asthma rates in Hackney and the City of London are higher in males below 15 years old, and higher in females above 15 years old.

14 Sexual Health

Questionnaires have revealed that many disabled people feel that they are seen as not having a sexual identity, however the fact that 50% of disabled adults surveyed in 2005 had been sexually active within the last year contradicts the idea of those with disabilities not having sexual relationships. [123]
Unfortunately evidence suggests that those with disabilities, particularly learning disabilities, face barriers in accessing sexual health services and sexual health information. [124]
Almost half (44.5%) of all disabled people surveyed in 2005 reported receiving no sexual education at school. [123]
Lack of education regarding sexual identity, sexual health and consent put those with disabilities at risk. A study in the Netherlands found that men with learning disabilities were eight times more likely to have a sexually transmitted disease than their peers without learning disabilities. [124] Research in Wolverhampton found that females with learning disabilities were over-represented within all those with teenage pregnancies making up 28% of teen pregnancies in the area. [125] This echoed the findings of an American literature review into teenage pregnancies which found a higher risk in those with a disability. [126] Disabled children and young people are also more vulnerable to coercion, which increases the risk that a sexual relationship may not be consensual. The increased risk of sexual abuse as well as other forms of abuse is discussed in Chapter 17.

By improving sexual education for children and young people with disabilities and ensuring that sexual health services are accessible, this may reduce the risk of sexually transmitted diseases, teenage pregnancy, sexual abuse and improve emotional wellbeing. The Department for Education and Employment highlighted the need for sexual and relationship education to meet the needs of children and young people with learning disabilities in 2000. [127]

There is a lack of robust national or local data regarding disability and sexual health.
For this reason it is not possible to comment on estimated level of need, unmet need or inequalities.

14.1 The Right Choice clinic

In September of 2016 a new service was launched at the Ivy Centre for those with learning disabilities. The Ivy Centre is a sexual health centre based at St Leonards Hospital. The aims of the service are to provide:

- Information regarding safe sex
- Testing and treatment for sexually transmitted infections
- Full contraceptive services
- Relationship advice and information

The service aims to remove barriers to care, for example by provides longer appointments at times where the clinic is less likely to be busy. Those who make an appointment are sent an easy read leaflet free of medical jargon explaining what to expect, which is discussed again when they attend. Those who use the service can choose to bring someone with them for support or attend on their own.

Due to the service being launched very recently there is not currently sufficient data regarding numbers and demographics of those utilising the service.

14.2 Key Points- Sexual Health

KEY POINTS

- Disabled people often receive less sexual health and relationship education than their peers.
- The government has emphasised the importance of sexual and relationship education for children and young people with learning disabilities.
- Studies suggest that those with disabilities are at higher risk of sexually transmitted diseases and teenage pregnancy.
- Disabled people are at higher risk of all forms of abuse including sexual abuse and coercion.
- There no robust data on the use of sexual health services by those with disabilities locally.
- In late 2016 a new, accessible local sexual health service for those with learning disabilities.

15 Priority areas of wellbeing

In addition to health needs, wider determinants of health also play a role in any child or young person's wellbeing. The following sections look in more detail at particular areas of wellbeing where are identified inequalities identified for disabled children and young people compared to their peers without disability.

16 Education

The Marmot Review, 'Fair Society, Healthy Lives' discussed the wider determinants of health, and acknowledged that educational outcomes affect not only future employment, but also physical and mental health. [128] It is therefore important to recognise inequalities in education and try to reduce any such inequalities where possible. Research has found that disabled adults are almost three times as likely to have no formal qualifications as their peers without disability. [4]

The percentage of children attending schools within Hackney and the City of London and are known to have special educational needs or disabilities is discussed in section 8.2.1 of this Needs Assessment. This section will discuss other educational measures and outcomes with regards to disability.

16.1 Community Special Schools

There are 65 state funded schools within Hackney and one state-maintained mainstream school within the City of London.

There are currently three community state-funded special schools in Hackney, there are none in the City of London. The Hackney special schools are The Garden School, Ickburgh School and Stormont House School. A brief outline of these schools can be found below, however further information about these schools and independent schools in Hackney is available on the Hackney Local Offer website.

16.1.1 The Garden School

The Garden School currently accepts pupils aged 4-16 years old with a diagnosis of autism who have severe learning difficulties.

16.1.2 Ickburgh School

Ickburgh School is for children aged between 3 and 19 years old who have profound and multiple learning disabilities, sensory impairment and severe learning disabilities.

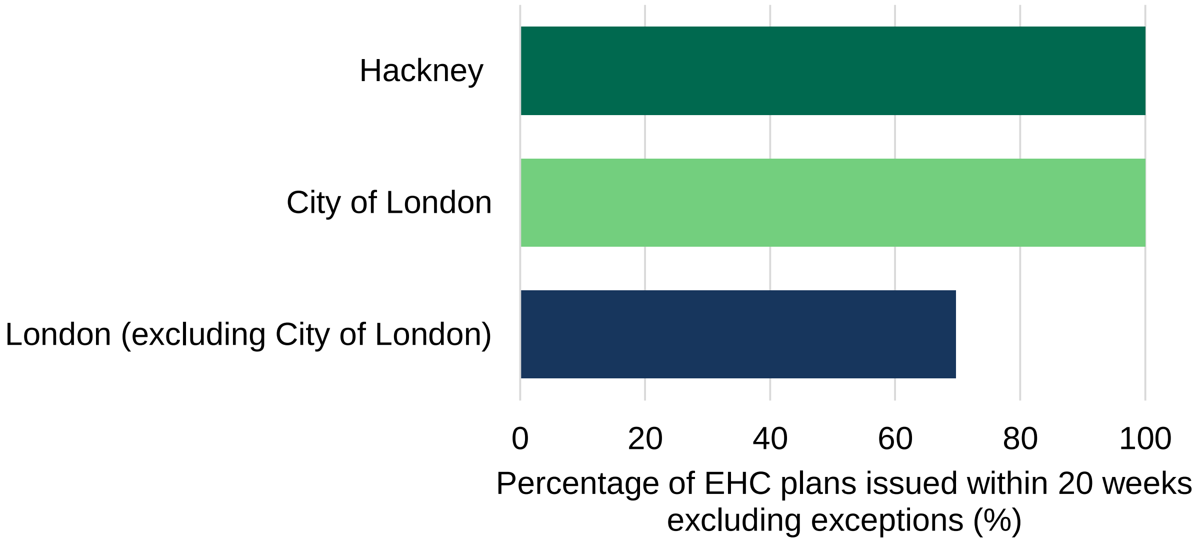
16.1.3 Stormont House School

Stormont House School is a school for pupils aged 11 to 17 years old who have complex and inter-related social and emotional, social communication or mental health needs.

16.2 Statutory timelines

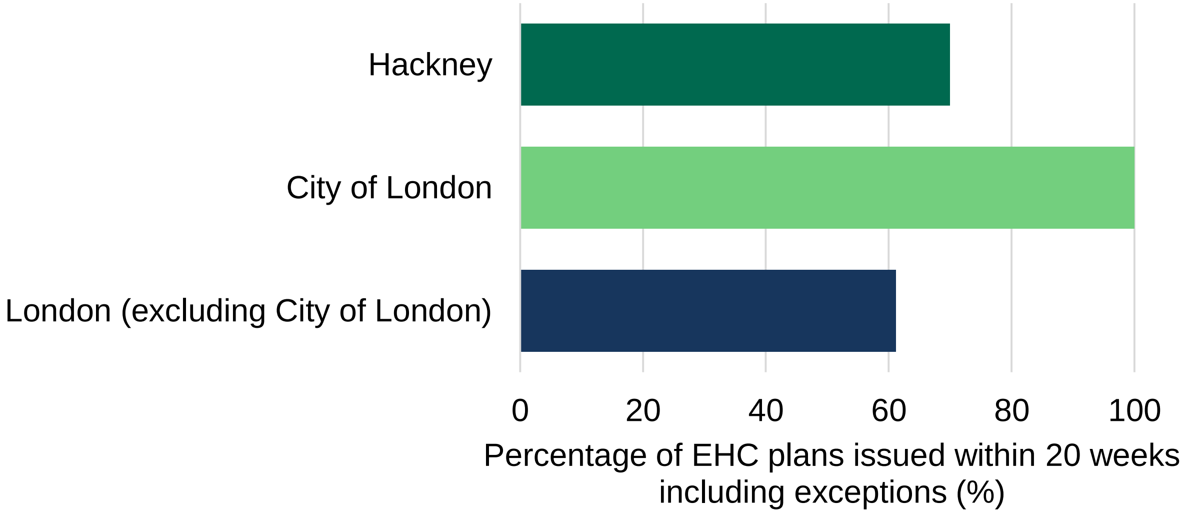
There is a statutory timeline on the provision of Education and Health Care Plans. Local authorities should carry out an assessment and if suitable issue an EHC plan within 20 weeks of receiving the request. In exceptional cases the LA is allowed to pass the 20 week time limit. Excluding exceptions, the City of London and Hackney LAs met the 20 week target in 100% of cases, far higher than the 69.7% average across London boroughs (excluding City of London) as displayed in *Figure 47*. Only two of Hackney's statistical peers also met the 20 week target in 100% of those excluding exceptions. [129] Including exceptions, the London average was 61.2% meeting the target, which Hackney exceeded at 70%. City of London still met the target in 100% of cases, as shown in Figure 48.

Figure 47: Percentage of EHC plans issued within the 20 week statutory timeline in 2015, excluding exceptions



Source: LG Inform. Proportion of new ECH Plans issued within 20 weeks, excluding exceptions. 2015. Department for Education
Note: Includes pupils of all ages from state maintained primary, secondary and special needs schools

Figure 48: Percentage of EHC plans issued within the 20 week statutory timeline in 2015, including exceptions



Source: LG Inform. Proportion of new ECH Plans issued within 20 weeks, including exceptions. 2015. Department for Education
Note: Includes pupils of all ages from state maintained primary, secondary and special needs schools

16.3 Absence Rates

The absence rate of a pupil is calculated using the total number of sessions (half days) from which they were absent and the total number of sessions possible. Illness is currently the most common reason for absence across England. [130] Pupils with a statement of special educational needs (SEN) or education healthcare plan (EHC) had an overall national absence rate of 6.8 per cent compared to 4.1 per cent for those with no identified SEN. Of all the primary type of need categories, children with profound and multiple learning difficulties had the highest rate of missed sessions at 13.7%. [131]

As fitting with the national data, both Hackney and the City of London absence rates are higher for pupils with known educational needs than peers without an identified SEN as shown in *Figure 49*. However, average absence rates for all children in Hackney (those with and without SEND) are below the average rates for both London and England as a whole. City of London has an absence rate for children with statements of SEN higher than the London average but equal to the England average. However, this is based on one primary school so it is not possible to generalise to all pupils within schools in the City of London.

Hackney has the lowest rates of missed school sessions for pupils with a statement of SEN (joint with Greenwich at 6.2%) amongst its statistical peers as shown in

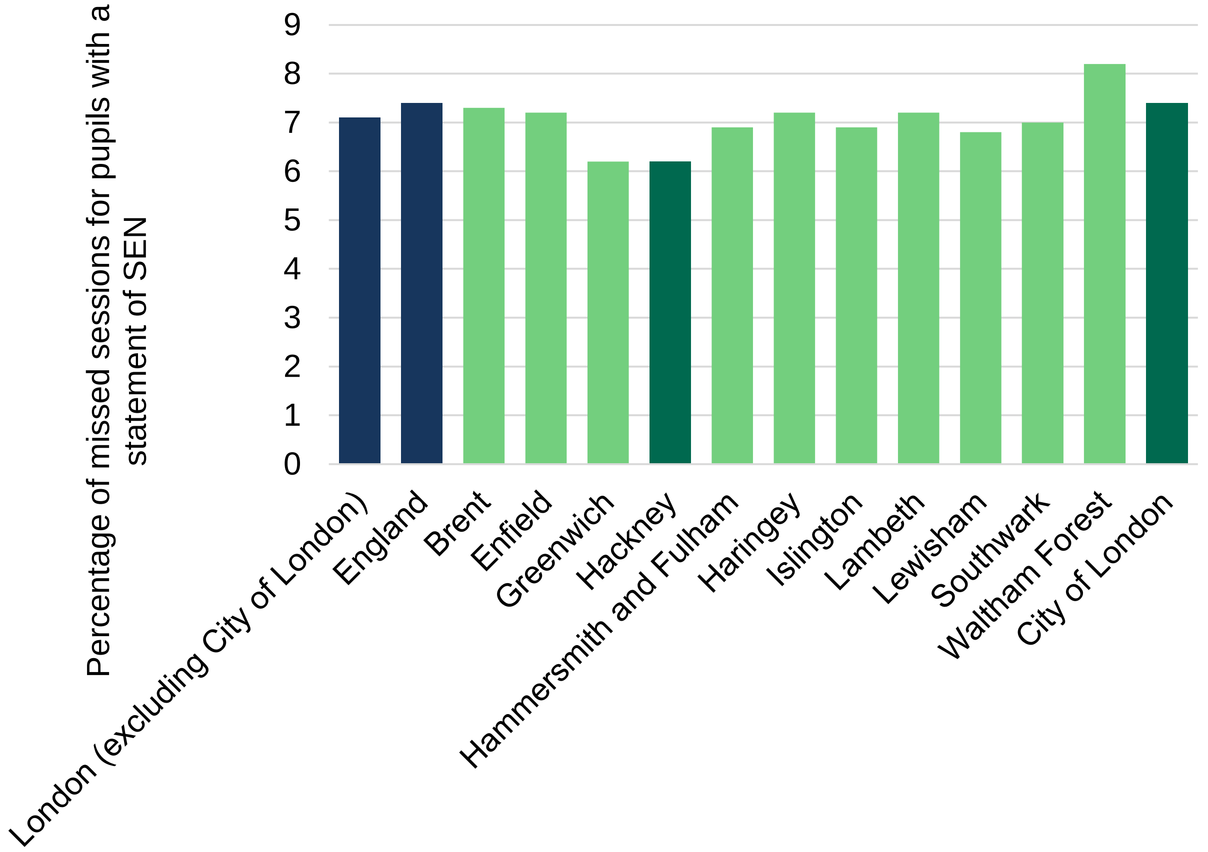
Figure 50. The rate for missed school session for SEN pupils without a statement in Hackney is 5.2%, as Figure 51 shows this is the fourth lowest within its group of statistical peers. The most recent comparable data available is for the academic year 2013/2014 so it is unclear whether this reflects the most recent academic year also. EHC plans were first issues in September 2014 therefore the data refers to those with a statement of SEN only.

Figure 49: Percentage of school sessions missed due to overall absence and percentage of persistent absentees within state-funded schools for the school year 2013/2014

	Hackney	City of London	London (excluding City of London)	England
SEN with a statement	6.2%	7.4%	7.1%	7.4%
SEN without a statement	5.2%	3.5%	5.6%	6%
No identified SEN	3.8%	3.3%	3.9%	4.1%
Persistent absence, with a statement of SEN	7.7%	0%	10.4%	10.8%
Persistent absence with no identified SEN	2.1%	0%	2.2%	2.6%

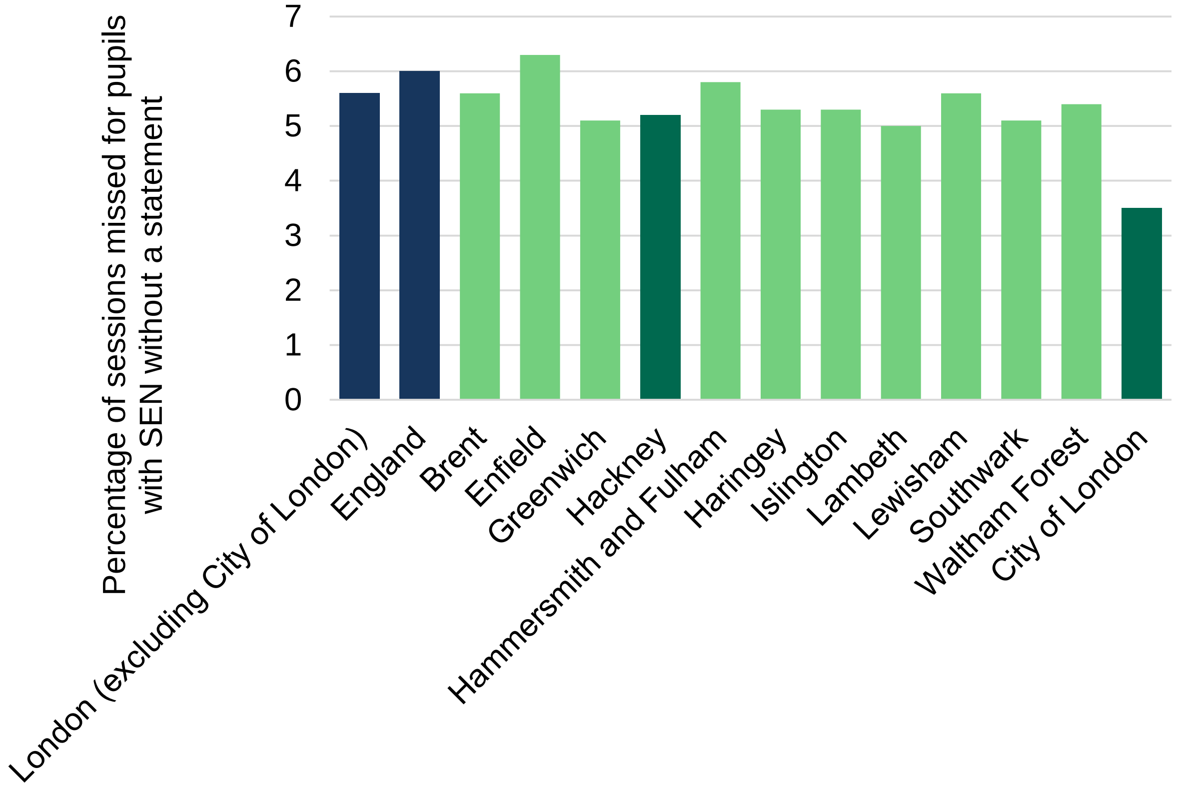
Source: Local Government Association. 2013/2014 Academic year data. Department for Education [132]
Note: Includes pupils of all ages from state maintained primary, secondary and special needs schools

Figure 50: Percentage of school sessions missed for pupils with SEN with a statement within state-funded schools (academic year 2013/2014)



Source: Local Government Association. 2013/2014 Academic year data. Department for Education [132]

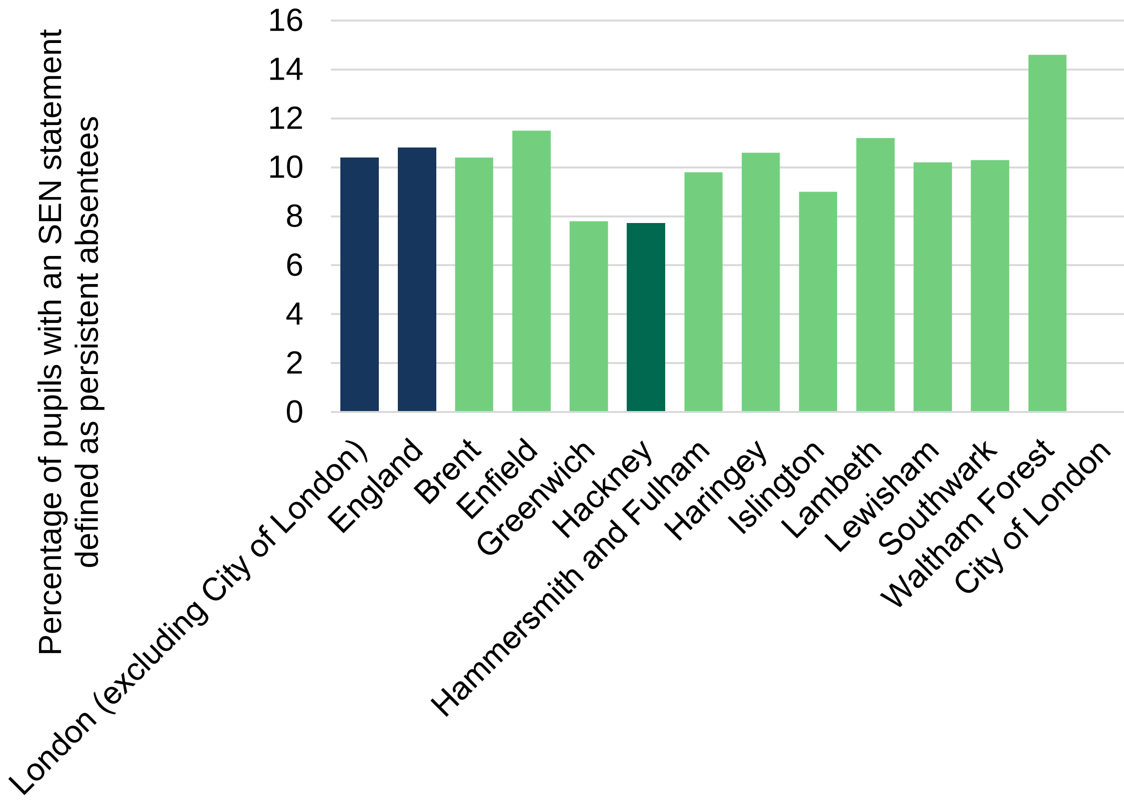
Figure 51: Percentage of school sessions missed for pupils with SEN without a statement within state funded schools (academic year 2013/2014)



Source: Local Government Association. 2013/2014 Academic year data. Department for Education [132]

Persistent absence is a term used to describe pupils who are absent for 10% or more of their possible sessions, this definition has been used since September 2015. The percentage of pupils across England with a statement of SEN or an EHC plan that are persistent absentees is more than two times higher than the percentage for pupils with no identified SEN. [130] The most recent comparable local authority based data seen in Figure 52 shows that Hackney has the lowest percentage of pupils with SEN statements defined as being persistent absentees. However, as shown in *Figure 49* the rate of persistent absence in children with statements of SEN (7.7%) is over three times higher than those without an identified SEN (2.1%).

Figure 52: Percentage of SEN pupils with a statement of SEN defined as persistent absentees within state-funded schools for the academic year 2013/2014



Source: Local Government Association, 2013/2014 academic year data. Department for Education [133]

16.4 Fixed period and permanent exclusion

There are only two legal forms of exclusion; fixed-term and permanent. The decision to exclude a pupil from school can only be made by the head teacher of the school.
Fixed period exclusion (at times referred to as suspension) is where a child is temporarily removed from school. A child can have fixed period exclusion for a maximum of 45 days in a school year. [134] Permanent exclusion means the child is expelled from school. The local council has a duty to arrange full-time education from the sixth school day of exclusion.

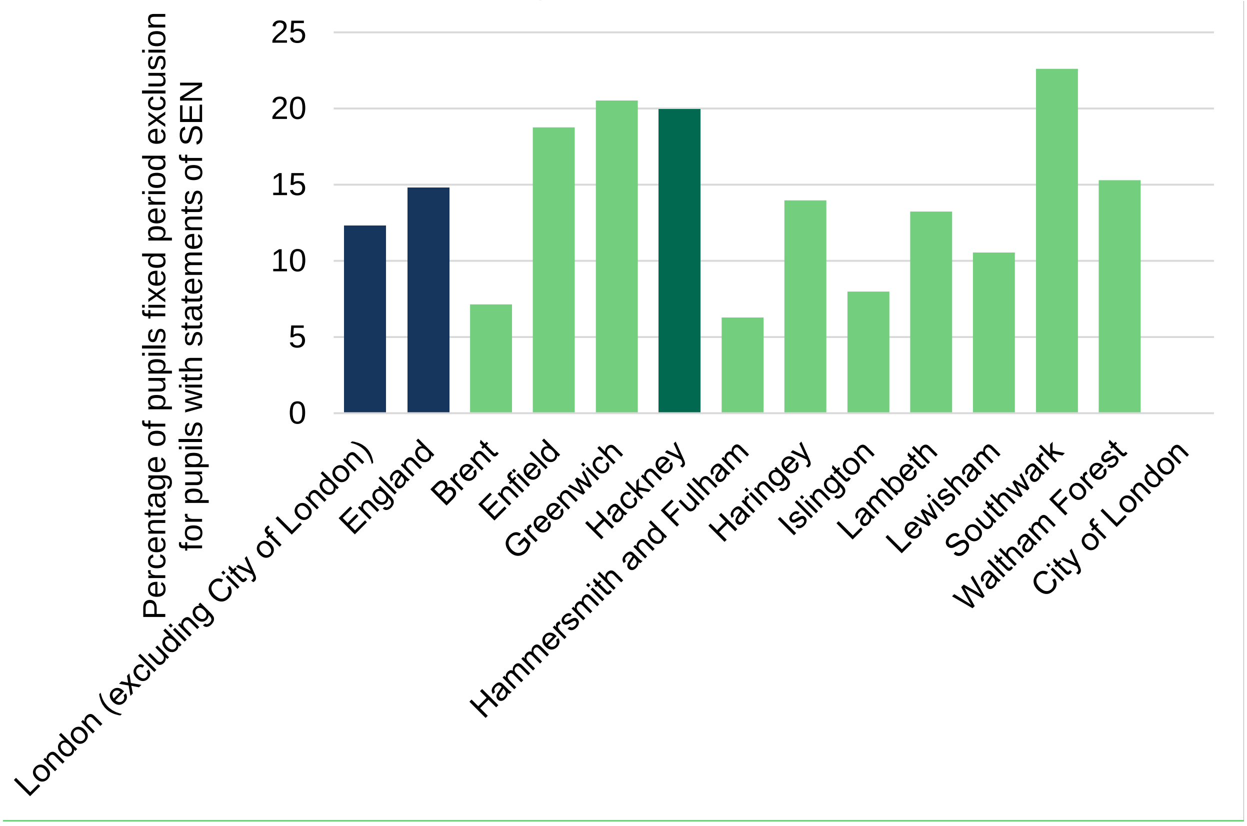
Nationally the rate of fixed period exclusion is higher in pupils with a statement of SEN than those without an identified SEN as shown in Figure 53. This is replicated in Hackney, however the rates in Hackney are higher than the London and England averages for both those with and without SEN. Hackney has the third highest percentage of pupils with statements of SEN having fixed period exclusions amongst its statistical peers as shown in Figure 54. The City of London fixed period exclusion figures are too small to comment on without affecting pupil confidentiality. The state funded primary school in the City of London had zero permanent exclusions in the academic year 2013/2014. The rate of permanent exclusion in Hackney for those with statements of SEN was too small for comment.

Figure 53: Percentage of pupils attending state-funded schools with fixed period and permanent exclusion in the academic year 2013/2014

	Fixed period (pupils without SEN)	Fixed period (pupils with a statement of SEN)	Permanent (pupils without SEN)	Permanent (pupils with a statement of SEN)
Hackney	13.5%	20.0%	0.04%	X
City of London	16.2%	X[15]	0%	0%
London (excluding City of London)	8.0%	12.3%	0.04%	0.04%
England	10.5%	14.8%	0.03%	0.09%

Source: LG Inform. Fixed period and permanent exclusion data for the academic year 2013/2014.

Figure 54: Percentage of pupils with fixed leave exclusion who have statements of SEN in state-funded schools in the academic year 2013/2014



Source: LG inform. Fixed period exclusion data for the academic year 2013/2014.

16.5 Attainment and Qualifications

Pupils are assessed throughout their school lives. Educational outcomes for children with special educational needs and disabilities can therefore be compared to those without an identified SEND as this data is captured by schools and reported to the Department for Education.

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[15] X represents a number of pupils (between 1 and 4) too low to comment on due to pupil confidentiality.

16.5.1 Early Years Foundation Stage Profile

The Early Years Foundation Stage Profile (ESFPS) is an assessment carried out in the academic year that a child becomes five years old. It is an assessment of their development and is conducted by their teacher over 17 early learning goals. A 'good level of development' is defined as meeting 7 of the 17 early learning goals.

As shown in Figure 55, the proportion of pupils achieving a good level of development at the ESFPS stage is higher in those who do not have an identified SEN than those pupils who do. This pattern is also seen in Hackney where 36% of children who have identified SEN without a statement achieving a good level of development compared to 73% with no identified SEN. Hackney ranks third highest amongst its statistical peers for those pupils with SEN but without a statement.
Unfortunately the figures for those with a statement of SEN in Hackney and all those with SEN in City of London were too low to publish (x in Figure 55).

Figure 55: The percentage of pupils achieving good level of development at foundation stage in the academic year 2011/2012

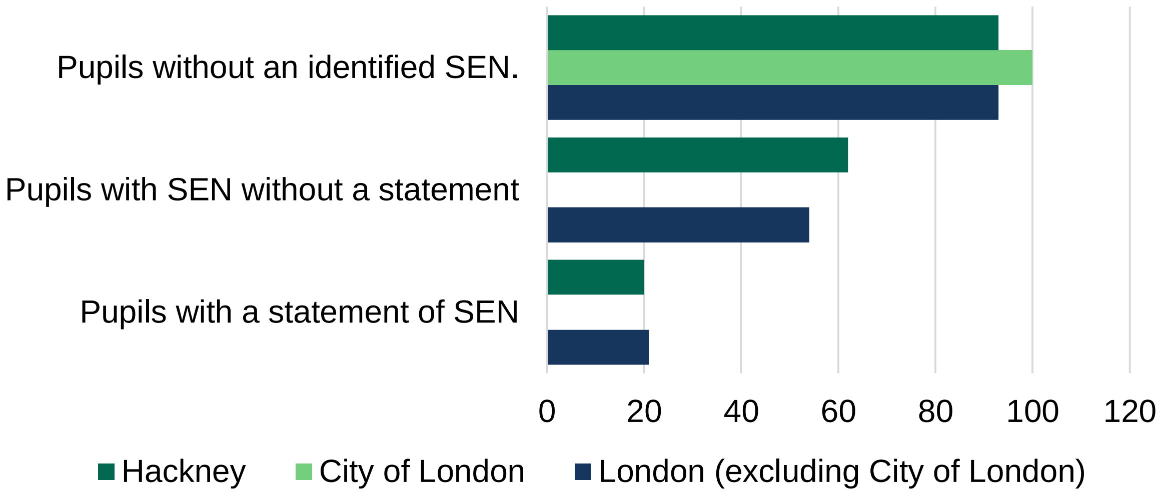
	Hackney	City of London	London (excluding City of London)
Pupils with a statement of SEN	x	x	10
Pupils with SEN but without a statement	36	x	29
Pupils without an identified SEN	73	76	70

Source: LG Inform. % of pupils achieving good level of development at foundation stage. 2011/2012 academic year. Department for Education.

16.5.2 Key Stage 2

Children attending state-funded primary school are assessed prior to moving on to secondary school in Key Stage 2 exams. In these exams pupils are expected to achieve a level 4 or above. Across the country, a lower proportion of pupils with SEN achieve a level 4 or above in reading, writing and mathematics. Figure 56 compares the level of attainment between Hackney, City of London and London (excluding City of London). As shown, Hackney has a higher level of attainment of level 4 and above for students with SEN (62%) without a statement than the London average (54%), higher than seven of its statistical peers. City of London figures for students with SEN (with or without a statement) are too low to be published. Twenty per cent of pupils in Hackney with a statement of SEN achieved level 4 or above in reading, writing and maths, 1% lower than the London average, ranking fifth amongst its statistical peers.

Figure 56: Percentage of pupils attaining level 4 or above in reading, writing and mathematics in the academic year 2014/2015



Source: LG Inform. Local area SEND Information 2014/2015. Department of Education.

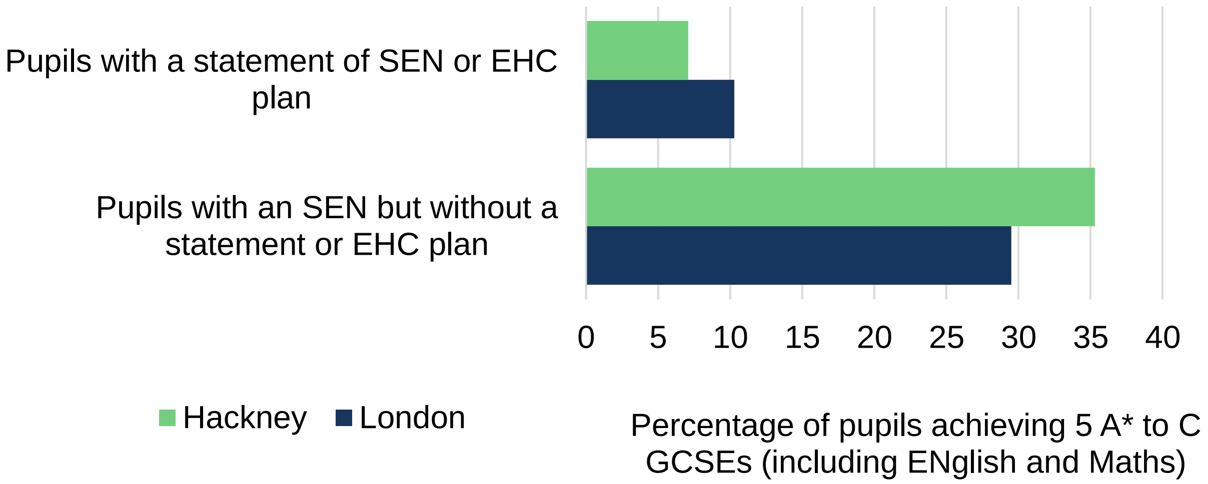
16.5.3 Key Stage 4 (GCSE)

GCSE attainment results are often broken down in to the proportion of pupils achieving either 5 A* to C GCSEs including English and Maths or 5 A* to G GCSEs. The data for City of London SEN students (both with and without statements of SEN/EHCP) achieving either 5 A* to C or 5 A* to G GCSEs is too low to publish. The rates for Hackney are shown in Figure 57 and Figure 58.

When looking at the proportion who achieve 5 or more A* to C grades, the rate in Hackney for those with a statement of SEN or an EHC plan is lower than the London average and 8th amongst its statistical peers at 7.1%. However, the figures for those with SEN without a statement or EHC plan is the highest of its statistical peers at 35.3%, far above the London average of 29.5%.

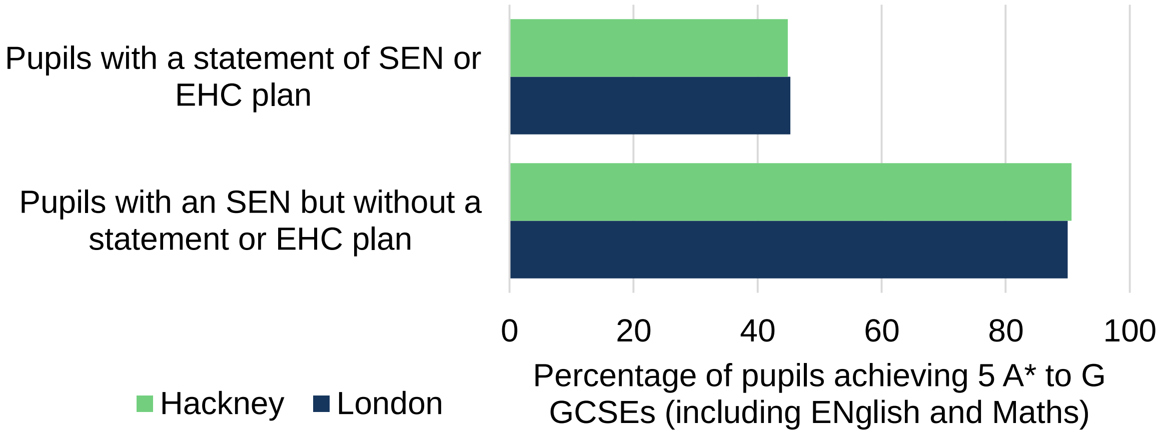
The proportion of pupils with SEN achieving 5 or more A* to G grades at GCSE is almost identical to the London average, with Hackney having the fifth highest proportion of its group of eleven statistical peers for those with and without statements of SEN or EHC plans.

Figure 57: Percentage of pupils achieving 5 or more A to C GCSEs (including English and Maths) in the academic year 2014/15.*



Source: LG Inform. Local SEND report. 2014/15. Department for Education.

Figure 58: Percentage of pupils achieving 5 or more A to G GCSEs in the academic year 2014/15.*



Source: LG Inform. Local SEND report. 2014/15. Department for Education.

16.5.4 In Education, Employment, or Training at age 17.

Data on the proportion of pupils with SEND who are in education, employment and training at age 17 can be found in the Transition chapter, section 0.

16.6 Key Points - Education

KEY POINTS

- City and Hackney has met the 20 week target for provision of Education, Health and Care plans in 100% of cases (excluding exceptions).
- Including exceptions, City of London met the 20 week target in 100% of cases, Hackney met the target in 70% of cases (compared to the London average of 61.2%).
- Absence and persistent absence is higher in pupils with special educational needs and disabilities (SEND) than pupils with no SEND nationally, and in Hackney and the City of London.
- Both fixed period and permanent exclusion rates are higher for pupils who have SEND both nationally and locally in Hackney.
- Attainment in Early Years Foundation Stage Profile, Key Stage 2 and Key Stage 4 is lower in pupils with SEN support compared to those without an identified SEND. It is lower still for pupils with a statement of SEN or an EHC plan.

17 Safeguarding and Looked After Children

Studies have shown that disabled children are particularly vulnerable to abuse. [135] An American study estimated that disabled children are 3.4 times more likely to be abused. [136]

Research suggests that adverse experiences in childhood can have a long-term negative effect. A report by Public Health Wales identified that of those with four or more adverse childhood events 25% were diagnosed with one or more chronic diseases in adulthood, compared to 7% in those with no adverse childhood events. [137] They identified adverse childhood events as: verbal abuse, physical abuse, sexual abuse, parental separation, household domestic abuse, household mental illness, household alcohol abuse, household drug use and a household member being incarcerated. Therefore by being at higher risk of abuse (an adverse childhood event), children with disabilities are at increased risk of having chronic health conditions in adulthood regardless of any other underlying health conditions.

17.1 Bullying via social media

Those with special educational needs were 12% more likely to report having experienced cyberbullying compared to their peers without SEN. Those who reported having a disability were almost twice as likely to report experiencing cyber-bullying than their non-disabled peers. [138]

17.2 Crime and disability

In 2016 the Equality and Human Rights Commission published a report into crime and disability. The report found that disabled 10-15 year olds were almost twice as likely as their peers without disability to be a victim of crime (22% compared to 12%). [139] Boys were more likely to be victim of crime, with 25% of disabled boys compared to 14% of non-disabled boys experiencing crime. Of disabled girls surveyed 18% were the victim of a crime compared to 10% in girls without a disability.

17.3 Children In Need

The Department for Education collates data from children’s social care services from each local authority in England annually. It gains data on all ‘children in need’, which they define as a child who has been referred to and is assessed as requiring social care services. [140] The Children Act (1989) identified all children with disabilities as being ‘Children in Need’. [28]
At 31st March 2016, there were 394,400 Children in Need across England. Of those 37,760 (10%), were recorded with the primary need at assessment of ‘child's disability or illness’. The most common disability among disabled Children in Need was learning disabilities, with 45.7% recorded as having a learning disability. [140]

The Department for Education collates data from children’s social care services from each local authority in England annually. It gains data on all children on a ‘Child Protection Plan’. At 31st March 2016, there were 50,310 children on a Child Protection Plan across England.

17.3.1 Known to local services

Hackney

At 31st March 2016, Hackney had 2,821Children in Need. Of these, 182 (6%) had a primary need at assessment of ‘child’s disability or illness’, below the England average.

As at 31st March 2016, 226 children in Hackney were on a Child Protection Plan. Six of these children (2.7%) had a disability. [140]

City of London

As of 1/12/16, fewer than 10 children on a Child In Need (CIN) plan had a recorded disability of a total of 13 children with a CIN plan. [141]

17.4 Looked After Children

Looked after children, also known as children in care, are under the care of the local authority. This may mean they are living with their parents under the supervision of children's social care, living with foster carers, living in semi-independent settings, in a residential children's home or living in other residential settings (such as secure units or schools). [141] A child may be placed under the care of the local authority if children's social care feel they are at significant risk of harm, or parents may voluntarily place their child under the care of the local authority if they are struggling to cope. Studies have identified that looked after children are more likely to experience mental health problems than their peers. It is estimated that 45% of looked after children in England aged 5 to 17 will have a mental health disorder. [142]

In England over the 2014-15 period there were 31,070 entrants to care (or young people recently defined as 'Looked after'), 670 of which had the category of need at the time of becoming looked after classified as 'child's disability', equating to 2.2% of looked after children. [143]

17.4.1 Known to local services

Hackney

At 31st March 2016there were 325 looked after children in Hackney, of whom 50 (15%) were recorded as having a disability.

City of London

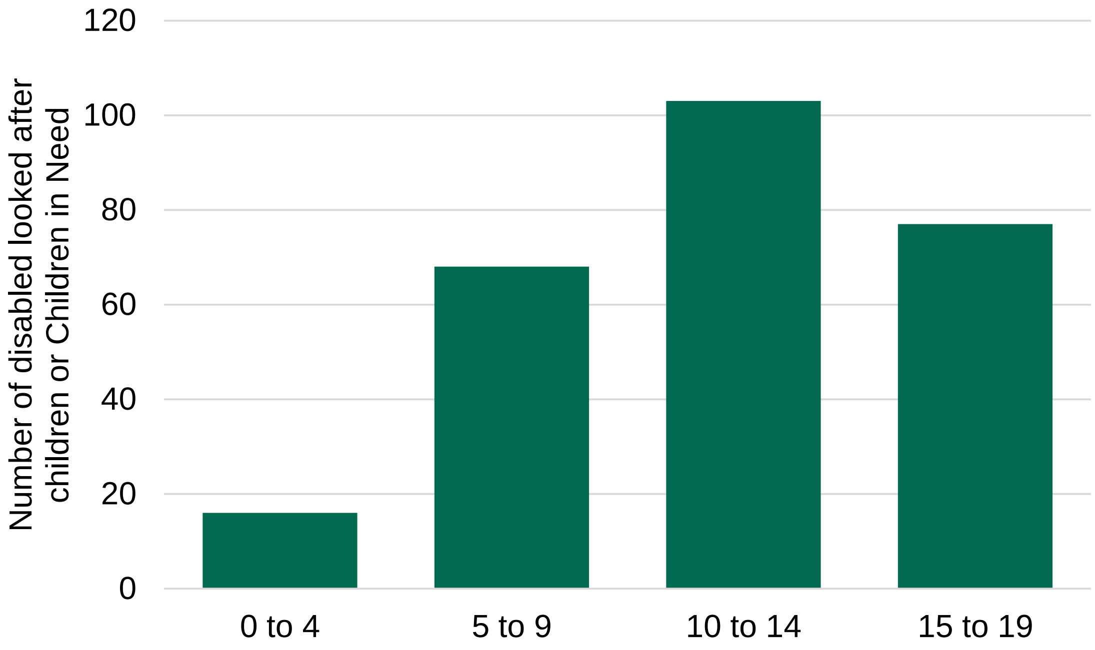
There were under 10 entrants to care (or young people recently defined as 'Looked after') in the City of London as of the 1st of December 2016, none of whom were recorded as having a disability.

17.5 Inequalities

17.5.1 Age

The ages of looked after children and Children in Need identified as having a disability are displayed in Figure 59 below. As shown, the majority were in the 10-14 age group. Age data for the City of London was not available as numbers were so low.

Figure 59: Disabled looked after children, and disabled Children in Need by age group.



Source: Hackney Children and Young People's Services [146]
Note: ages taken from a snapshot of data from 31st March 2016

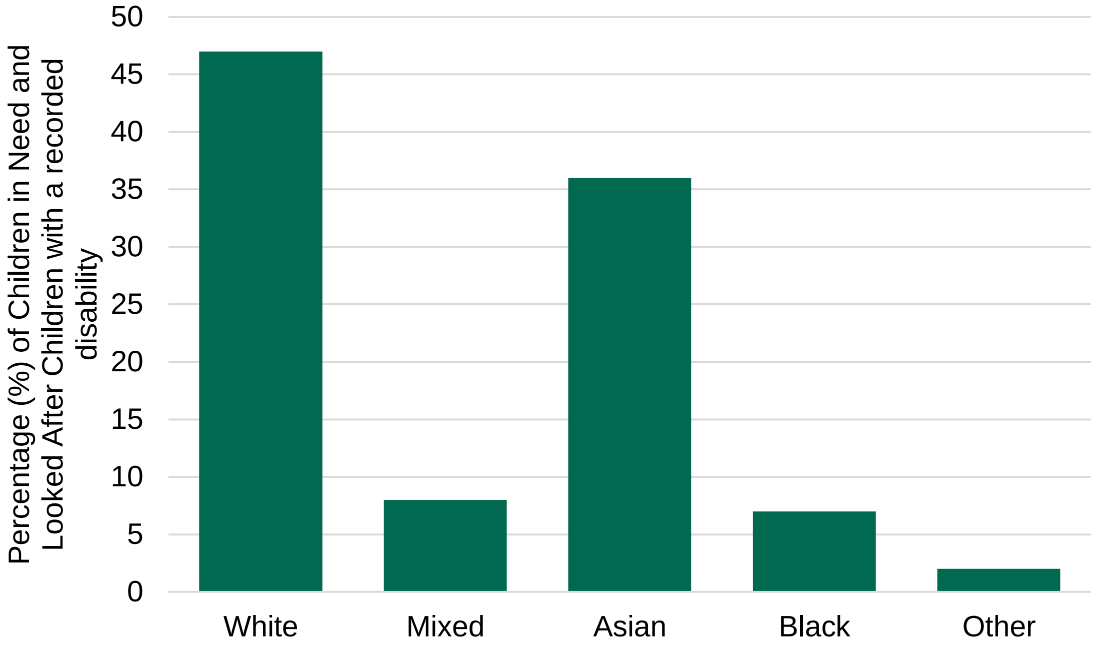
17.5.2 Gender

Of the 264 disabled Children in Need or looked after children in Hackney (snapshot of records from 31st March 2016), 86 (33%) were female, and 178 (67%) were male. Gender data for the City of London was not available as numbers were so low.

17.5.3 Ethnicity

Of the 264 disabled Children in Need or looked after children (snapshot March 2016), almost half were white (47%) as shown in Figure 60. Data for the City of London was not available as numbers were so low.

Figure 60: Percentage (%) of Children in Need and ~~L~~looked ~~A~~after c~~C~~hildren known to have a disability in Hackney, by ethnic group.



Source: Hackney Children and Young People's Services. [146]

17.5.4 Disability

Children and young people's services determine the impact of an individuals' disability into the following groups:

Disability	Description
Mobility	Getting about the house and beyond.
Hand Function	Holding and touching.
Personal Care	Eating, washing, going to the toilet, dressing, etc.
Incontinence	Controlling the passage of urine or faeces.
Communication	Speaking and/or understanding others.
Learning	Having special educational needs, etc.
Hearing	A condition affecting hearing.
Vision	Condition affecting vision.
Behaviour	A condition entailing behavioural difficulties, includes attention deficit hyperactivity disorder (ADHD).
Consciousness	Seizures.
Diagnosed with autism of Asperger syndrome	Diagnosed by a qualified medical practitioner as having classical autism or Asperger syndrome. Do not include children who have merely been identified as having an autistic spectrum disorder (ASD), e.g. by their school. This can be associated with the behaviour and learning categories above.
Other DDA	One or more of the child's disabilities under the Disability Discrimination Act 2005 does not fall into any of the above categories.

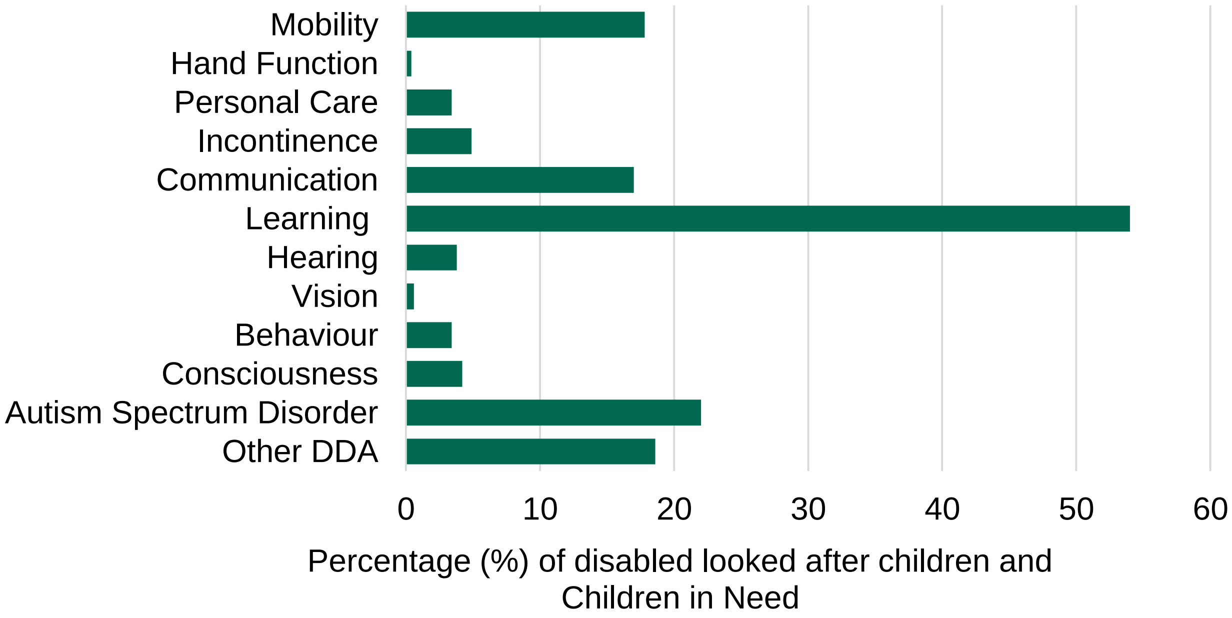
Source: Hackney Special Educational Needs and Disability Team (2016) [146]

KEY POINTS

- Children with disabilities are more likely to be victims of abuse.
- Children and young people with disabilities are at increased risk of bullying via social media, and are twice as likely as their peers without disabilities to be a victim of crime.
- The most common disability amongst looked after children and Children in Need is Learning Disabilities (over 50% of those that have a special educational need or disability)
- There are double the number of disabled male looked after children and Children in Need compared to disabled females.

A child or young person can have more than one recorded category of disability.
The recorded disabilities of looked after children and Children In Need is found below in Figure 61. The most common disability was Learning Disability with over half being recorded as having a learning disability (56%), this was followed by Autism and Asperger's syndrome (22%).
Disability for children in City of London with a Child In Need plan is too low to comment upon.

Figure 61: Recorded disabilities for disabled looked after children and Children in Need in Hackney



Source: Hackney Special Educational Needs and Disability Team (2016) [146]

17.6 Key points- Safeguarding

18 Finances

Research suggests that 4 in 10 families with a disabled child live in poverty. [144] The reasons for this are multi-factorial. One factor that contributes to poverty is that the annual cost of raising a child with disabilities is three times higher than a child without disabilities, with families spending on average £550 per month on disability related expenses (such as specialist equipment, food, clothing, transportation etc.). [45] Due to these additional costs households with a disabled member are twice as likely to have unsecured debt totalling more than half of the household income, and are three times as likely to use doorstop loans.

Disabled children are more likely to be living in workless households, with 38% in a workless household compared to 16% of all children. In addition to this, in households where a parent is working their earning are on average lower per week and per hour (estimated to be £23 lower per week in 2011). [144]

A 2016 report by the New Policy Institute discussed the potential impact of Universal Credit on those with disability, of significance it reduced the disabled child addition to half its current size. [10] This reduction will likely exacerbate the levels of poverty for families caring for disabled children.

The current benefit system for disabled children entails Disability Living Allowance (DLA) and Personal Independence Payments.

18.1 Disability Living Allowance

To be eligible a child has to be under 16 and have walking difficulties and/or require additional care to a child their age without disabilities.
It is split into a care component (assistance with day-to-day self-care) and a mobility component (assistance with mobility). The care component is split into lowest, middle and highest rates with increasing money available for those with additional higher levels of need. The mobility component is split into lower and higher rates, with the higher component providing additional finances in comparison to the lower rate.
DLA is usually paid monthly and can vary from £21.80 to £139.75 per week depending on the level of need. [145]

18.2 Personal Independence Payment

Personal Independence Payments (PIP) have replaced Disability Living Allowance for those aged 16 to 64. As with DLA the rates available range from £21.80 to £139.75 a week and is also broken down into two components. The daily living component is either classified under standard or enhanced for those with higher needs, and mobility component which is again split into standard or enhanced rate. [146]

18.3 Direct Payments

If a family is receiving support from social services they can apply for direct payments. Direct payments (DP) allow the individual or their family to select and pay for the care services they require. Their introduction aimed to allow more individual choice with regards to social care providers. However, they may mean that the parents of a disabled child then become employers. [147] Employer responsibilities may include setting up a payroll, employer's liability insurance and requirements such as Statutory Sick Pay and redundancy pay.

18.4 Known to local services

On the 23rd of November 2015 there were 1,019 children and young people receiving DLA in Hackney.

There were fewer than ten under the Special Educational Needs and Disability Service receiving PIP.

As of the 8th of December 2016 there were 61 children and young people below 18 receiving direct payments in Hackney.

This data was unavailable for the City of London.

18.5 Inequalities

18.5.1 Gender

Gender data is not currently captured by the Special Educational Needs and Disability Service for those receiving DLA and PIP.
Of the 61 individuals receiving direct payments, 13 were female (21%) and 48 (79%) were male.

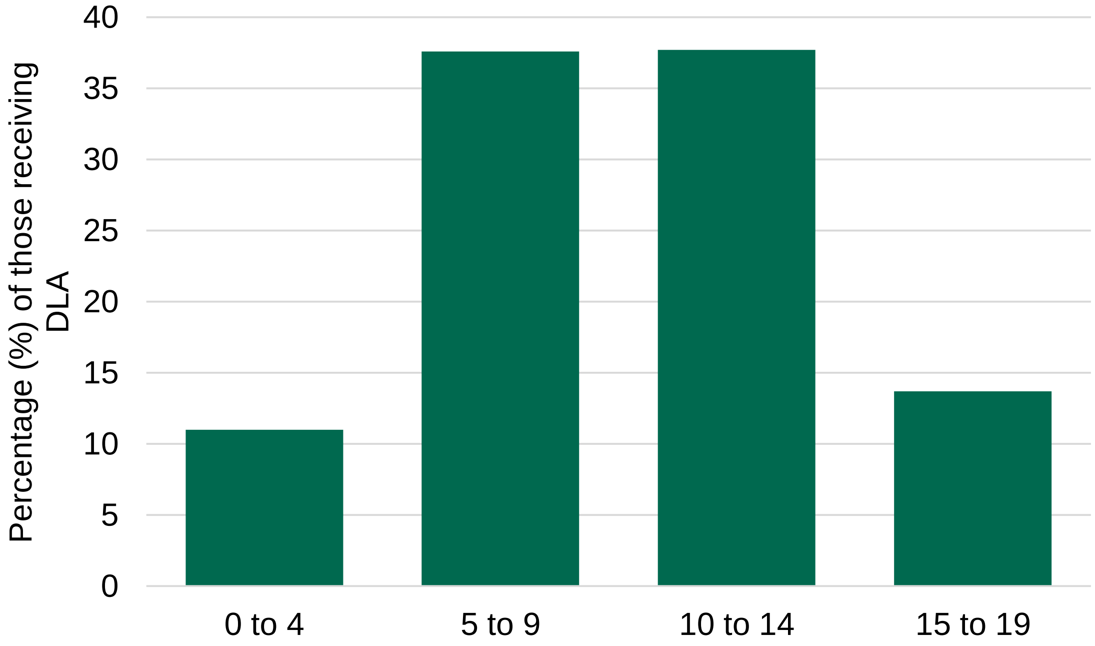
18.5.2 Age

As the number of children and young people receiving PIP in Hackney was below ten, it is not possible to comment on ages due to confidentiality issues.

DLA

Of the 1019 children and young people receiving DLA in Hackney in November of 2016, the majority (75%) were aged 5 to 14 as shown in Figure 62 below.

Figure 62 Receiving DLA in Hackney in 2016, by age group

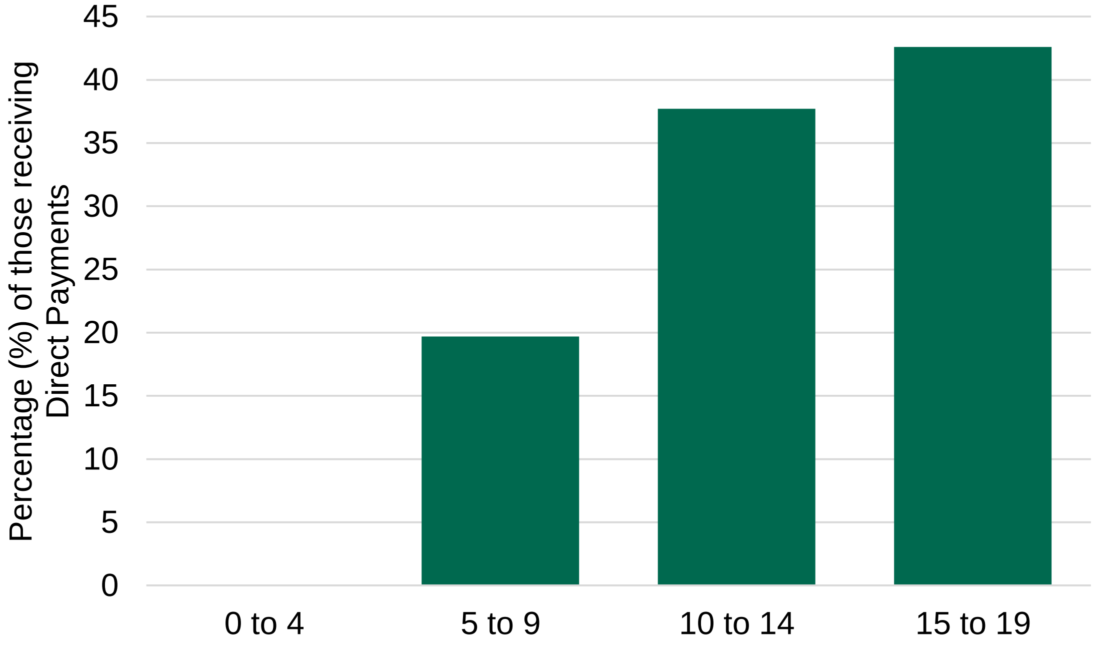


Source: Disabled Children's Service (2016)

Direct Payments

The majority of those receiving direct payments were in the 15-19 year old age group, followed by 10-14 year olds as shown in Figure 63 below.

Figure 63: Number of people receiving Direct Payments in Hackney in 2016, by age group

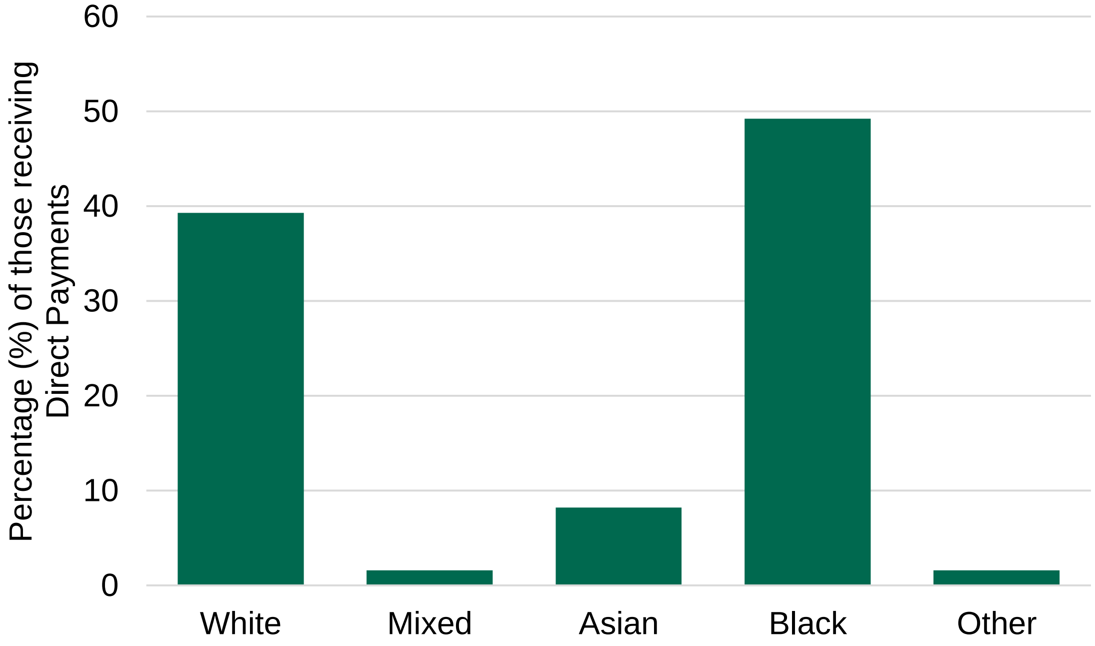


Source: Hackney Learning Trust (2016)

18.5.3 Ethnicity

Ethnicity is not captured for those receiving DLA and PIP in Hackey.
Almost half of those receiving Direct Payments were recorded as being Black as shown in, the second largest ethnic group were those of white ethnicity.

Figure 64: Ethnicity of those receiving Direct Payments in Hackney in 2016



Source: Hackney Learning Trust (2016)

18.5.4 Deprivation

Postcode data was not available for those receiving Direct Payments, Disability Living Allowance and Personal Independence Payments.

18.5.5 Disability

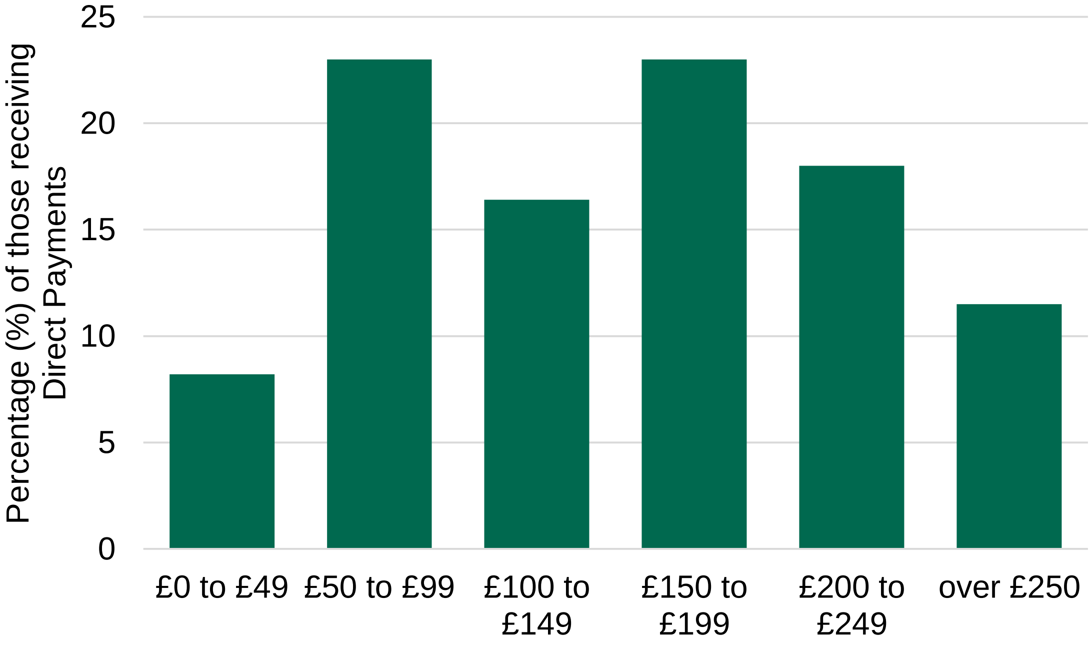
DLA

Although data on specific disabilities was not available, data on the care component of DLA received was captured. The care component is split into low rate, middle rate, and high rate, with those receiving high rate having higher levels of care needs than those receiving low rate. Fewer than 5 children were receiving the low rate of care component with approximately 53% receiving the middle rate and 47% receiving the high rate care component.

Direct Payments

Although data on specific disability was not available for those receiving Direct Payments, the total money received per individual gives an idea of the level of severity of their disability. Of those receiving Direct Payments the rat received weekly ranged from £29.38 to £744.13.

Figure 65: Average sum of support being received by people in receipt of Direct Payments in Hackney



Source: Hackney Learning Trust (2016)

As shown in Figure 65 above, the majority of those receiving Direct Payments were receiving between £50-99 and £150-199 per week. The data above suggests that fewer families with a child with less severe disabilities are choosing to receive Direct Payments.

18.6 Key Points- Finances

KEY POINTS

- 4 in 10 disabled children are living in poverty.
- Raising a child with disabilities is more expensive than a child without disabilities.
- It is estimated that disability related costs add up to an additional £550 a week.
- Those under 16 years old can receive Disability Living Allowance, whereas those over 16 can apply for Personal Independence Payments.
- Families can apply to receive Direct Payments, allowing them to choose their care providers. However, they will take on the role of employer and the additional responsibilities associated.

19 Transition between child and adult services

The National Institute of Clinical Excellence (NICE) defined transition as a

> "purposeful and planned process of supporting young people to move from children's to adults' services". [50]

However the term transition can also viewed as preparation for adulthood, and including issues such as independence, employment and qualifications.

It is has been identified that young adults with disabilities face inequalities in all these areas. A third of those with a disability aged over 16 report experiencing barriers to education and training, which is almost double those without a disability. [4]

The importance of preparation for adulthood and gaining independence are an important part of the lives of all individuals. The Marmot review states:

> Without life skills and readiness for work, as well as educational achievement, young people will not be able to fulfil their full potential, to flourish and take control over their lives. [128]

Statutory regulations and guidelines from organisations such as NICE are in place to aim to improve the transition process for children with disabilities. For example the SEND Code of Practice states duties such as:

- Local Offers must identify training opportunities, apprenticeships and other support available to provide a smooth transition from education to training and employment.
- Schools should engage with Further Education providers to help plan for transition.
- Transition planning must be built into EHC plans, and should begin when a child is 14 years old. [40]

NICE guideline recommendations include:

- Involving young people and their carer's in transition services design.
- Ensuring that the young person is registered to a GP practice and has a named GP.
- Transition planning should start in Year 9 (age 13 or 14) at the latest.
- Annual transition reviews should be conducted, they should occur more frequently as required.
- The young person should have a single professional acting as their 'named worker' to oversee and coordinate the transition process.
- Young people, their parents and carers should be encouraged to be involved in their transition planning.
- The young person should continue to be supported following transition to adult services as required. [50]

19.1 Number in Education, Employment or Training

A way of assessing whether there has been a positive transition to adulthood is by measuring the number of individuals who are in Education, Training or Employment.

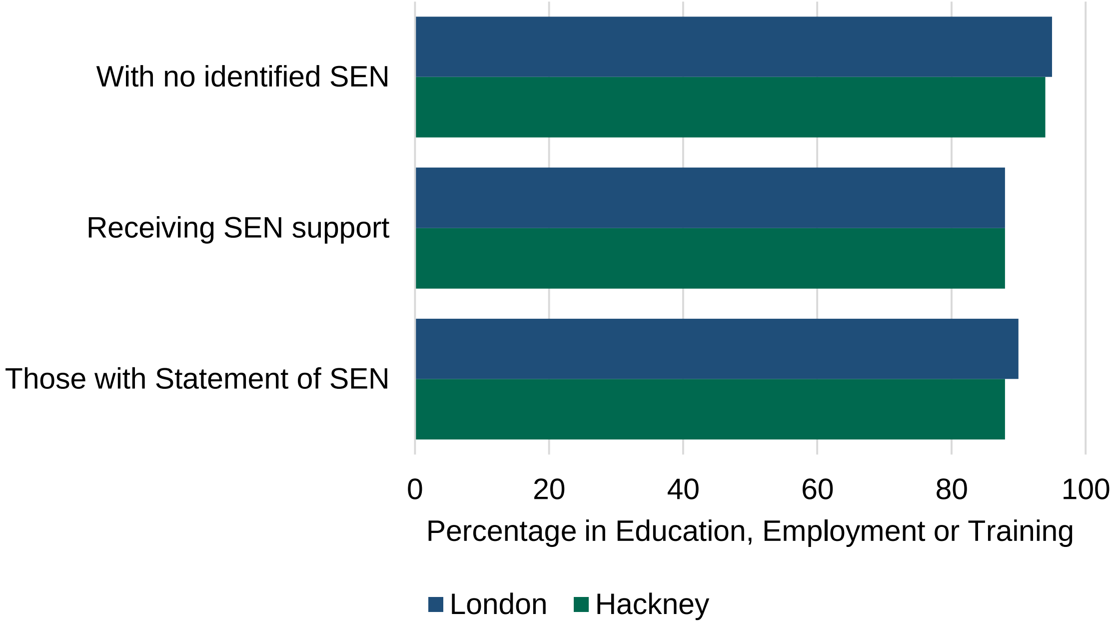
19.1.1 Number in Education, Employment and Training at 17

To be included in the measure of those in education, employment or training at age 17 the young person must have participated in the first two terms after completing key stage 4 (GCSE).

The London average of young people in Education, Employment or Training at age 17 without an identified SEN is 95%, Hackney is slightly lower at 94%.

The rate across London for those with SEN (either SEN support or statement of SEN) was lower than those without an identified special educational need or disability. This was also found in Hackney as displayed in Figure 66 below. Data for the City of London was suppressed due to low numbers.

Figure 66: Percentage of students in Education, Employment or Training at age 17 for the 2014/15 academic year in Hackney and London.



Source: LG Inform. Destinations of key stage 4 and key stage 5 pupils. Department for education. 2014/15 academic year.

19.2 Settled Accommodation

Another possible means of assessing transition arrangements is looking at how many individuals are living in settled accommodation. Settled accommodation refers to those living in secure medium or long-term accommodation. Unfortunately adults with learning disabilities are more likely to be living in unsettled accommodation than their peers without a disability. Across London 59% of those with learning disabilities in the year 2011/12 were living in settled accommodation. Hackney had a higher proportion, with 65% living in settled accommodation. City of London had the highest proportion of adults with learning disabilities living in settled accommodation (86%), however this is based on a smaller number of adults with learning disabilities. [148]

19.3 Paid employment

Data is also available for the percentage of those with a learning disability in paid employment. The London average for the year 2015/16 was 7.7%. Hackney had a lower proportion with only 2.4% of adults with learning disabilities in paid employment, whereas the City of London had 0%. [148]

19.4 Hackney Learning Trust - Education Health & Care Plans

Hackney Learning Trust (HLT) uses a database to track pupils with Education Health Care Plans - the CAPITA One system – which records the SEND data for returns to the Department for Education down to the level of individual Education Health and Care Plans. At the time of writing, this database was not able to follow individuals, their demographic details and their service needs throughout the full transitions process. As a consequence an Excel spreadsheet is the main method used to capture data from other sources and is currently the main tool used for tracking young people approaching, or in the midst of, transition. Monthly transitions monitoring meetings are coordinated by Hackney Learning Trust and attended by colleagues from Children's Social Care, Adult's Social Care, related health teams (including CCG representative), Young Hackney, Prospects and other agencies to track and monitor individual cases throughout this process.

As of the 1st of September 2016 there were 126 18 year olds captured on this Transitions Monitoring Spreadsheet. This represents 18 year olds with EHC Plans or Statements of SEN.

19.5 Transitions in Social Care

The Disabled Children's Service is based within the SEND Service in Hackney Learning Trust and provides support to the most vulnerable children with disabilities and their families. As of March 2016, the Disabled Children's Service was working with 233 children and young people.

As the children they work with reach the age of 17 the service carries out a Transitions Assessment (known as a 'Section 5&6 Assessment) and refers the case to adult social care ready for transfer at the 18th birthday.

The number of cases transferring to adult social care in recent years are shown below, the majority of clients (almost all) have a primary need listed as learning disability.

Figure 67: Number of cases transferred to adult social care from the Disabled Children's Team in Hackney per year

Calendar Year	Cases Transferred to Adult Services at age 18
2014-15	24
2015-16	21
2016-17	16

Transition Health Outreach Team

This service based at Hackney Ark supports children and young people with disabilities who are not eligible for social care services. Young people living in Hackney aged 14-19 with a disability can access the service.

They can either self-refer or be referred by professions at schools, healthcare services, or occasionally social care. The team help young people to:

- Develop health action plans
- Transition to further education
- Access health, fitness and leisure activities
- Travel independently by offering travel training
- Access mainstream services by offering the services advice, training and support
- Access appropriate services by signposting and referrals. [149]

Some individuals may not be accepted by the service. Those whose needs are too high are referred to social care. There are also some young people who do not wish to engage with the service. They are advised to self-refer back to the service if they change their minds.

In November of 2016 there were 43 young people being supported by the team.

19.6 Young Hackney

Young Hackney is the Council's early help, prevention and diversion service for children and young people aged 6-19 years old and up to 25 years if the young person has a special education need or disability. The service works with young people to support their development and transition to adulthood by intervening early to address adolescent risk, develop pro-social behaviours and build resilience.

The service offers outcome-focused, time-limited interventions through universal plus and targeted services designed to reduce or prevent problems from escalating or becoming entrenched and then requiring intervention by Children's Social Care. Children and young people are also encouraged to engage with universal opportunities through Young Hackney's network of youth hubs and commissioned projects. This allows them to join a range of positive peer groups and allows staff to monitor progress and sustain support.

19.7 Inequalities

19.7.1 Gender

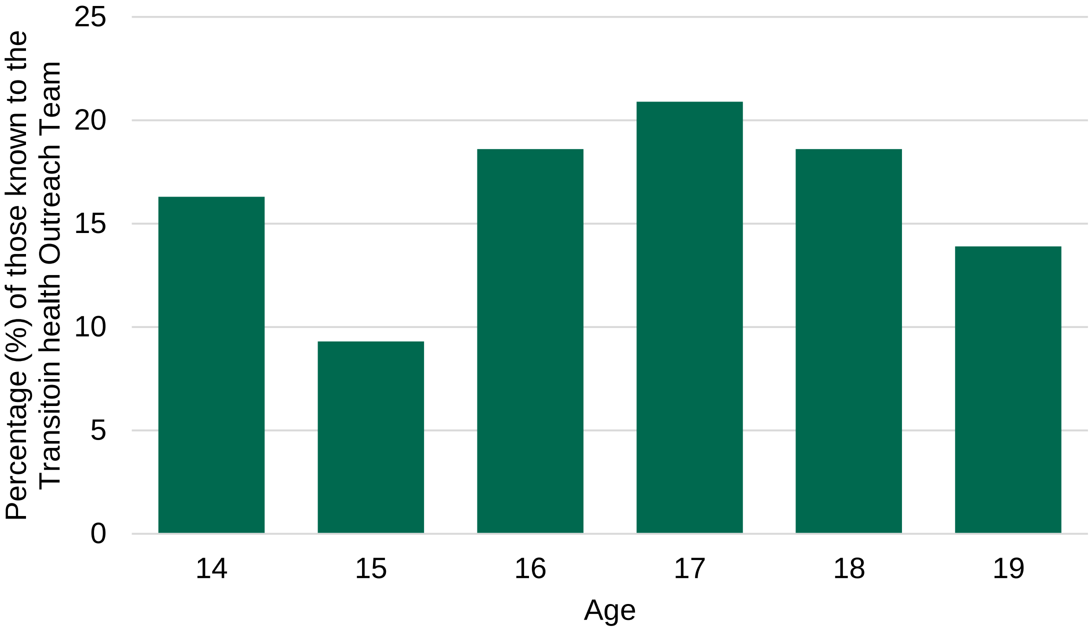
Of the 126 18 year olds with an EHC plan known to HLT, 40 (32%) were female and 86 (68%) were male.

Gender data was not recorded for those under the Transition Health Outreach Team.

19.7.2 Age

Of the 43 with an open case under the Transition Health Outreach Team (THOT), the majority were aged 17 as shown in Figure 68 below.

Figure 68: Ages of those being supported by the Transition Health Outreach Team in November 2016



Source: Transition Health Outreach Team (2016)

19.7.3 Deprivation

Postcode data was not available for those with EHC plans on the HLT transition spreadsheet or those known to the Transition Health Outreach Team.

19.7.4 Disability

Of the 43 open cases known to the THOT, 17 (39%) have ASD and 10 (23%) have a moderate learning disability. The remaining 38% have a range of disabilities but numbers are too low to comment upon without compromising patient confidentiality.

19.8 Key Points- Transitions

KEY POINTS

- There are currently weaknesses in information sharing during the transitions process, with some evidence of a lack of early engagement between children's and adult's services
- The transition to adulthood (for young people engaged with local statutory services) has been highlighted as a period which can exacerbate offending behaviour (and likelihood of contact with the criminal justice service), especially where services are poorly planned or unclear.
- 94% of those identified to have a Special Educational Need or Disability in Hackney are in education, employment or training at age 17.
- 65% of adults with learning disabilities in Hackney are living in settled accommodation, compared to the London average of 59%.
- 2.4% of adults with learning disabilities in Hackney, and 0% of those in the City of London are in paid employment. Across London, the average proportion of adults with learning disabilities in paid employment is 7.7%.

20 User Feedback- Parent Focus Group

To gain qualitative feedback from parents and carers of disabled children a focus group was organised.

20.1 Organisation

A parent focus group was held (Wednesday 23rd November 2016) with members of Hackney Independent Forum for Parents/Carers of Children with Disabilities (HiP). Parents were invited to attend by the chairs of the organisation and were sent information regarding the focus group if they wished to participate. This information sheet is included in Appendix 3. The chairs of the parent organisation then selected a group of parents with children with a range of disabilities and a range of ages.

Organisation of a focus group for parents from the Orthodox Jewish community was attempted using a parent group whose information was provided by Interlink. Unfortunately, the parent support group 'In Touch' felt they were not able to assist in inviting parents to attend. For in depth report into the views of the Charedi population with regards to health and developmental services for children and young people, a report entitled 'Community Insight Report: How Charedi Children and Young People Access Child Health and Development Services' was published in December 2014 by Interlink in partnership with Healthwatch Hackney and City and Hackney CCG. The findings were based on interviews with stakeholders in education and community providers who work with disabled children as well as questionnaires completed by members of the Charedi community.

20.2 Focus Group Attendees

A total of 12 parents attended the focus group (including 2 chairs of HiP), there were three fathers and nine mothers in attendance.

The group as a whole were parents to 14 children and young people with disabilities.
The fourteen children consisted of 9 boys and 5 girls.
The age of the children varied as outlined below:

Age	Number of Children
5-9	5
10-14	6
15-19	3

The children of the parents attending had a range of disabilities. These included Autistic Spectrum Disorder, developmental delay and physical health disabilities (including red blood cell disorders and epilepsy). Some children had more than one disability.

Although the parents cared for children of a variety of ages and disabilities, due to the number of those in attendance the feedback is not possible to generalise to the whole community. For further information on limitations please see section 22.7.

20.3 Format of Focus Group

The focus group took place over approximately 90 minutes and was facilitated by a member of the Public Health team. It began with an ice-breaker introduction and covered their thoughts and experiences regarding the following topics:

- Identification, diagnosis and assessment of disability
- Health services
- Education services
- Leisure facilities and Short Break services
- Child and parental involvement in decisions
- Recommendations for change

20.4 Focus Group Feedback

The audio recording of the focus group was transcribed and analysed using the analysis method framework. [150] Direct quotes from the parents in attendance have been divided by theme and are in green within quotation marks. Quotes which may jeopardise a child or parent's confidentiality have been excluded.

20.4.1 Identification and diagnosis of disability

The parents in attendance had varying experiences regarding the identification of their child's disability. For some parents the disability was diagnosed antenatally, for others shortly after birth and for some when the child was older.

One parent was informed of her child's diagnosis over the telephone and expressed her feelings that diagnoses should be given in person and that counselling should be offered to parents when the diagnosis is made.
'Make sure when a diagnosis is given, that it isn't given over the phone. You know, when I received information about my child's condition, all that did was send me into a spiral of depression. But, what should have happened was some kind of counselling and a face-to-face diagnosis.'

Parents expressed the importance of professionals being well informed on the condition with which their child was diagnosed, as this allows parents to ask questions and be aware of what to expect for their child’s future.

‘Information is important, it is not just the diagnosis, but actually in terms of when parents ask questions, how will this affect his life? It needs to be correct information.’

20.4.2 Holistic Individualised Care

All the parents in attendance agreed that treating the child holistically and an as individual was vital in ensuring their health and wellbeing needs were met.

‘I think treat the child holistically, it’s like our children are dissected according to whatever clinics they attend, so the whole of the child is not assessed.’

‘Professionals, whether in the hospital or wherever should stop generalising these children, they should be treated as an individual, and we should be listened to by professionals in our children’s care.’

20.4.3 Multi-disciplinary care and communication between professionals

An aspect of care that many of the parents at the group found frustrating was that they felt there was a lack of multi-disciplinary meetings and joint working between the professionals involved in their child’s care.

‘One person is treating the brain, one is treating the spine, it needs to be holistic. You need to have all the people dealing with your child in the same room at the same time. You know, it saves some time.’

Another aspect of care parents highlighted related to the practicalities of receiving services from a multi-disciplinary team. This was with regards to communication between professions. Some parents found that is an issue not only within health services but between health and education and within the education system.

‘You see different people every week, and then they have to collate the information. You know, with the NHS, you would think there was a main database, but there isn’t. One specialist has to wait for one thing, then another specialist has to wait for another.’

20.4.4 Early Intervention

Numerous parents vocalised their belief that their children would have benefitted from receiving support and accessing services as soon as possible after diagnosis to help to prevent the situation from becoming more severe. One mother whose child has a physical disability summarised her thoughts on early intervention:

‘If you do not have that early intervention, you keep going through the same circles. A lot of things came later on, like physiotherapy. She has to have regular physiotherapy at Great Ormond Street now, she’s at CAMHS, she’s under OT, all these things, if they had been in place, we would be a lot better at dealing with it.’

Another mother expressed her frustration regarding the lack of early intervention for challenging behaviour she had received.

‘When I went to CAMHS, we mainly went because of challenging behaviour, my daughter is 5. When we went for the initial assessment, the kind of idea that I got, was that I was coping with the behaviour. So I was discharged and they said you can re-refer. And what I am thinking to myself, do I have to wait until I am pulling my hair out because I can’t deal with the behaviour to be referred to CAMHS? Is it not better to have some kind of process going on beforehand, so that if I do reach that stage of pulling my hair out that CAMHS already knows this child, they already know what's going on, they already know the family?'

20.4.5 Continuity of Care

Parents expressed how their children struggled with seeing many different professionals as it often took numerous sessions for their child to trust and get used to the professional, leading to delays in possible progress.

'We as adults, do not click immediately with new adults and just take to them. These are children, they are in a different environment, and they are in a hospital. Children don't need that. It's like a miserable experience all round, and then they don't get that comfort of being with the same person, someone they've got to know.'

'The first three sessions the child has to learn to trust you, to be able to speak to you in the first place. There are some children, like my son when we went to the first one he didn't even say anything, he couldn't. They have to trust you first to be able to open up to you.'

Some of the parents also expressed how by not seeing the same professionals they felt exasperated at having to repeat the same information about their child at each visit.

'When I go to the doctor, any place, any professional, they always look at her file, and they always start from, how was your birth? Every time, they speak about from birth, and I am always explaining and explaining and we go back again. When my child is 20, then I'm going to have to explain again still.'

20.4.6 Specialist Training

Parents expressed how they felt professionals in health, social care and education need to be trained on how to support children with disabilities and what special considerations they need to put in place to meet their needs. This was mentioned numerous times, specifically with regards to those whose children had autism and issues of sensory overload.

'I think what doctors and specialists need to realise is that all of our children have special needs and they are all different. So when we go to see someone about their eyes or whatever, they have those little time slots to fit our children. My child in particular, when we get there she is starting to look around, and she is freaking out. If you are saying to me we only have half an hour, well it is going to take half an hour to calm her down.'

'When you're actually seeing the GP, the GP is almost like sighing, as if they have no idea that your child may be having sensory issues. They expect to just communicate with the child, with the young person, and expect a particular response.'

'Sensory issues, you can't underplay those, people really don't get that bit. Lighting, noise, change, they're huge.'

20.4.7 Involving the child and their parents in decision making

All the parents in attendance reinforced the importance of professionals involving them in their child's care. They explained how, as their child's carer, they understand their child's needs best.

'We are, along with our child, experts in their care and I think we are ignored, as people have said, whether it be talking to the consultant, talking to teachers, talking to the SENCO, GPs, whoever is out there.'

‘I think they need to be more consistent, and read notes, and listen to parents. And also, listen to the patient themselves, listen to the children, because they matter.’

Another aspect of involving the parents and the disabled child is communication and providing them with information relevant to their child’s care.
‘Before my daughter was at the special needs school she was having speech and language at the Ark, you would get a section of it, say 6 weeks and go home and do what they recommend. Once she was in a special needs school, the therapists are in the school and you do not get feedback from them of what they are doing with your child.’

‘I think just a breakdown of the them and us atmosphere, the welfare of the child is paramount, we want the welfare of our children, and they want the welfare of our children, so until we get together and understand we are both on the same page that is when we will have something that will work.’

20.4.8 Short Breaks and Leisure Facilities

Eleven of the twelve parents had accessed Short Breaks services. The majority preferred having the option of tailoring the service to meet their child’s individual needs.
‘I used Short Breaks services, but what I found easier for myself, rather than using their activities is applying for an individual budget and then I can tailor that towards my daughters individual needs. Because if you say to me, ‘take her to this specific place’ that may not be suitable for my daughter as she may go there and freak out because there are too many children.’

However one parent pointed out that although individualised budgets were useful for some, it was important to keep the option of having locally provided Short Breaks provisions.
‘I would hate for it to be one thing or another, when my son was a younger child the provided Short Breaks were brilliant, and towards the end individual budgets have been better, we need both.’

20.4.9 Education Services and Special Considerations

Parents discussed that they felt that education services, particularly mainstream education services, at times failed to make reasonable adjustments for their children. This was raised in regards to challenging behaviour in particular.
‘Particularly in the schools that are mainstream, the academies, this is something we hear all the time, that they won’t flex their behaviour codes, and they don’t treat parents as equal partners.’

‘We get a lot of phone calls about children who are at risk, at high risk of exclusion, mainly autistic but not exclusively, but because the behaviour issues are not being dealt with properly, because there is a bigger drive for discipline, there is a zero tolerance disciplinary approach and it doesn’t work for some of our kids.’

Two of the parents also discussed difficulties when their child was out of school due to illness, and expressed that there had been issues getting schools to provide work for their child to do whilst they recovered.
‘I asked them to call his school to get some work for him because half term was coming up, they did that and the school did not send any work for my son. So what they’ve agreed now, as soon as he’s off school and ill, whether he’ll be at home, or at hospital, I contact them and that kicks something in. There should be some kind of a protocol for them to send work home for him to do.’

20.4.10 Transition to adulthood

Only two of the parents had children who were going through the process of preparation for adulthood and transitioning to adult services.

‘They go through the process of leaving children’s services and going through to adult services and the care is lacking to say the least.’

‘I know that he is unlikely to meet the threshold for adult social care, because they’re not geared up for autism, they’re not geared up for behaviour, I am having to keep him where he is until he is sufficiently ready, he is not going to get any support. There is no sub-level of support for children who do not meet those thresholds.’

These parents and those with younger children were anxious about what would be available to their children when they reached adult age, and what support they would receive.

‘Adult social care services, learning disability services, they’re a bit rigid. It is not flexible for the needs of your young person. So if they’re not in education, and they’re not in training, there’s work going in around the support towards employment for young people with special needs, but there’s a way to go in Hackney.’

‘I’ve got a five year old and I’m thinking, if she is developmentally delayed at this stage when she turns 18 she will probably be presenting like a 9 or 10 year old. How do you expect her at 18 to be an independent adult if there are not provisions there? That is scary.’

20.4.11 Summary of parent feedback

The key themes throughout the focus group across all the topics were:

- The importance of communication between professionals in the multi-disciplinary team and with parents.
- The need to involve parents and the disabled child in decision making.
- Ensuring parents and their child have all the relevant information needed to be involved in decision making and advocate their views.
- Support and services should be holistic and individualised to cater to each child’s particular needs.
- Professionals supporting disabled children and their families should have specialist training to assist them on meeting their needs.
- Where possible there should be continuity of care to ensure that the disabled children and young people are seeing the same professionals consistently.

Ensuring that this occurs will help improve the health and wellbeing of disabled children and young people and their families. Unfortunately currently the parents felt that services were not meeting all of these points, meaning that parents felt they had to fight for their child’s needs to be met.

‘You cannot underestimate how much the parent of a disabled child has to be a warrior, from day one. Particularly around education, but also around everything else.’

20.5 Charedi Community Parent Feedback

The Charedi Community Insight Report published by Interlink entitled ‘Community Insight Report: How Charedi Children and Young People Access Child Health and Development Services’ had similar feedback to the parent focus group conducted for this Needs Assessment. There were particularly similarities with regards to the want for professionals to listen to parents and involve them in decision making and the value parents place on early intervention provisions. However specific recommendations were raised by the Charedi community including:

- The difficulty for non-Yiddish speaking therapists to engage with children and young people, particularly with regards to Speech and Language Therapy.
- Mixed-gender group therapy sessions or opposite-gender therapists for older children and young people is a barrier to accessing services.
- Mixed gender parent groups may also limit access.
- With regards to CAMHS services, parents may feel reluctant for their child to speak to health professionals in case there was an influence on their spirituality and mind-set.

21 Stakeholder Interviews

As well as gathering the views of parents caring for disabled children, qualitative data was also gathered by interviewing a variety of professionals working in services for disabled children and young people (both universal services and specialist disability services).

21.1 Interview Questions

As the interviews involved numerous professions who are involved in the care and support of disabled children and young people the questions were broad to allow those from any sector to feel able to answer.

- What is the role of the **organisation/service?** What is your role within the organisation?
- Does the organisation/service have **eligibility criteria** (age, gender, disability, location of residence, ethnicity, Disability Living Allowance etc.)?
- Can you describe the standard **pathway** into your service?
- How well do you feel the **health needs** of disabled children and young people are being met in the local area?
- How well do you feel the **wellbeing needs** (wider determinants of health) for disabled children and young people are being met in the local area?
- How do you feel the demand on your service has changed since the 2014 Children and Families Act and introduction of **Education, Health and Care plans**?
- What are the main **barriers** that impact the health and wellbeing of disabled children and young people in the local area?
- What **recommendations** would you make to improve the health and wellbeing of disabled children and young people in the local area?

21.2 Stakeholder List

A total of 24 individual stakeholders were interviewed from education, health, social care, the voluntary sector and the Charedi community. Two of those interviewed held two roles with regards to supporting disabled children (explained in table below).

This section gives an outline of who was interviewed, the role of their organisation, the pathway to accessing the service/organisation and eligibility criteria.

Organisation	Role	Pathway into Service. Brief description of Service.	Eligibility criteria
City and Hackney Clinical Commissioning Group	**Clinical lead for Mental Health Services (including CAMHS) and Clinical lead for Children's Services.**	The CCG covers all those who are registered at a GP practice in Hackney and the City of London. Responsible for commissioning local health services.	Those registered to GP surgeries in Hackney and the City of London. Children's health services (including CAMHS) cover those up to age 18.
City and Hackney CCG	**Non-clinical management lead for Children's Services**	As above	As above
City and Hackney CCG	**Children's commissioning lead for the CCG**	As above	As above
City and Hackney CCG	**Designated Medical Officer for Education (also Consultant Community Paediatrician at Hackney Ark)**	As above	As above, however for those with SEND up to the age of 25.
City of London Local Authority	**Head of Education for SEND- SEND project manager**	Those referred for an EHCP or those identified by the state-funded primary school as having SEND.	All City of London residents aged 0-25 with an EHCP and all those attending the state-funded primary school with SEN support.
City of London Local Authority	**Public Health- Children's Lead**	Automatically covers all residents of the City of London up to 18 years old.	Encompasses all residents of the City of London aged up to 18
City of London Local Authority	**Lead for SEND and Early Years**	Automatically covers all residents of the City of London with an SEND up to the age of 18 (or 25 with an EHC plan)	All residents of the City of London with an SEND (up to the age of 25 for those with an EHC plan)
City of London Children's Social Care	**Team Manager, Family & Young People's Service**	Via the Multi-Agency Referral Form. Can self-refer or be referred in by education, healthcare or other professionals. Team sits within Children's Social Care.	Residents of the City of London up to the age of 18 (those over 18 would come under the care of Adult's Social Care)
Hackney Ark	**Consultant Community Paediatrician (also the CCG's Designated**	Assesses children who have been referred to developmental clinic.	Children and young people who are registered to a GP practice that is part of City and Hackney CCG

	Medical Officer for Education)		up to the age of 18 (up to 19 if attending a special school)
Hackney Learning Trust	**Head of SEND at Hackney Learning Trust (also the head of the Disabled Children's Service)**	Those referred for an EHC plan assessment or those recorded to have an SEND on the school census who are attending state-funded schools in Hackney.	Residents of Hackney with an EHC plan up to the age of 25 or those attending state-funded Hackney schools identified as requiring SEN support up to the age of 18.
Hackney Disabled Children's Service	**Head of Disabled Children's Service Team (also the head of SEND at Hackney Learning Trust)**	Specialist social work service for children and young people with disabilities. Referral to the service occurs via the FAST team to which parents, carers or professionals can refer.	Children who are residents of Hackney with disabilities up to the age of 18.
City and Hackney School Nursing Service	**Lead School Nurse**	Via school medical register (should include all health problems including mental health). School nursing service includes- safeguarding, school entrance and health assessments and supporting disabled children.	All children attending state-funded schools and academies in Hackney and City of London. Children are referred to the service via a medical register provided by each school.
Health Visiting Service	**Senior Health Visitor for Disability**	Children with disabilities may be identified via routine health visitor checks. Children new to the area are discussed at monthly GP practice meetings.	Children up to the age of 5 living in Hackney and the City of London.
Children's Disability Forum	**Coordinator Children's Disability Forum**	Parent, children and young people access the group. No referral required. Commissioned by the CCG.	Those aged 0-25 with a disability living in Hackney and the City of London
Garden School	**Head of School**	State-funded specialist school for pupils with autism. School must be named on the EHC plan.	Children aged 4 to 16. Must have a diagnosis of autism and an EHC plan.
Garden School	**Family Support Lead**	As above	As above
Ickburgh School	**Assistant Head Teacher**	State-funded community special school.	Children and young people aged 3 to 19 with profound and multiple

		Admission requires the school to be named on a pupil's EHC plan.	learning disabilities, sensory impairment or severe learning disabilities.
Woodberry Down Children's Centre	**Centre Manager**	Early years service for children under 5 and their families including health services, early education and family support. Families can self-refer or professionals can refer via a Common Assessment Framework.	Under 5 year olds and their families living in Hackney.
Interlink Foundation	**Chief Executive**	Supports community organisations and charities. Provides education to professionals on the Charedi community.	Works with Orthodox Jewish organisations and public sector professionals.
Interlink Foundation	**Policy Officer**	As above	As above
In Touch	**Welfare Advisor**	Parent Support Group. Can self-refer or referred by labour support workers or GPs.	Orthodox Jewish parents of children with disabilities. No threshold but intended for those with multiple or significant disabilities.
Satmar School for Boys	**Special Educational Needs Coordinator (SENCO)**	Parents select school. Independent mainstream school.	Orthodox Jewish boys from local community. From nursery to age 16. Mainstream school.
Beis Malka Girl's School	**Special Educational Needs Coordinator (SENCO)**	Parents select school. Independent mainstream primary school.	Orthodox Jewish girls from local community. From nursery to age 11.
Side by Side School	**Head Teacher**	Pupils have school named on Education, Health and Care plan.	Orthodox Jewish children (both genders). Nursery age up to 19. EHC plan required.
Children Ahead	**Service Manager**	Parents self-refer or referred by school. Provide speech and language therapy, physiotherapy and emotional support.	Orthodox Jewish boys. Usually do not meet the threshold for an EHC plan. Ages 3-16.
Children Ahead	**Chief Executive**	As above	As above

21.3 Feedback

Interviews were either conducted face-to-face or over the telephone. Transcripts were then analysed using the analysis method framework. [150] Direct quotes from the stakeholders have been divided by theme and are in green within quotation marks. Quotes which may jeopardise a child or family's confidentiality have been excluded.

Stakeholders were asked to answer the questions given their own experience with local families, children and young people. Therefore, the views of those interviewed may not represent the views of their entire organisation.

21.3.1 Identification and diagnosis of disability

An issue identified by some of the stakeholders was that of diagnosis of disability. Many disability services and benefits require a formal diagnosis and as one stakeholder identified, different services use different diagnostic or classification systems.

'A big problem is that there are so many definitions of disability and that there is a threshold that entitles you to a service.'

Another aspect of diagnosis raised was that some disabilities are easier to identify than others. Due to the difficulty of identifying those with less visible disabilities, those with learning disabilities or autism may be missed.

'Physical disabilities are more likely to be visible externally and more easily apparent therefore easier to identify, whereas learning disabilities can be harder to identify.'

'A major problem for parents is the issue of late diagnosis, those who are not diagnosed until school, which causes problems for them at school. This is mostly those with autism or Learning Disabilities.'

21.3.2 Thresholds

As mentioned above, thresholds and eligibility requirements for services were identified as a barrier to access by numerous stakeholders. The eligibility thresholds between services vary which can cause confusion and frustration for families involved and stakeholders referring to other services.

'There is a big gap for those who do not meet thresholds for services such as mild learning disability or autism, less so for mental health problems and physical disability.'

'We don't have joint up levels of thresholds for eligibility, we may think a child has complex needs and urgently needs housing but doesn't necessarily align with housing team eligibility criteria for allocation.'

21.3.3 Coordinated care

A fundamentally important aspect of the care of children and young people which was raised by almost all stakeholders interviewed was the importance of communication and joined-up working between different professionals and organisations involved in caring for those with disabilities. Many of those interviewed stated that communication with colleagues from other professionals at multi-disciplinary meetings was key to ensuring that children and young people with disabilities were referred to the appropriate services

Stakeholders also raised that information needs to be shared between organisations to facilitate coordinated care and ensure that all those involved with the disabled CYP are up to date.

‘Within health, we are quite good at liaising with the family, This is harder when there are many specialists and children are being seen at Great Ormond Street or the Royal London as it can be harder to get information. When children have complicated health needs it makes things complex. It is easier if they are attending the Homerton as we are all on the same system.’

‘Parents want a shared database for al professionals they see. They see one doctor who refers then to a specialist then they have to explain everything again, they go to a dentist and have to explain everything again. They are fed up of repeating everything.’

‘Information is shared but recorded on different systems. Health visitors can access GP records, however they need to physically go the GP surgery.’

21.3.4 Safeguarding

Some stakeholders felt that within their service child protection concerns could be easily flagged and followed up via multi-disciplinary meetings.

‘Safeguarding is dealt with through MAT and they work very closely with children’s social care. If there are safeguarding concerns it can be stepped up into children’s social care who can step it down back to MAT.

However it was raised that some stakeholders felt that child protection concerns when raised for children and young people with disabilities were not taken as seriously as for those without disabilities.

‘A barrier is sometimes when you make referrals to FAST they see the child has autism and refers them onto the Disabled Children’s team who don’t deal with the child protection concerns.’

21.3.5 Change in SEND legislation

All stakeholders were asked whether their organisation had experienced any change in demand since the reforms to SEND and the introduction of EHC plans. Some stakeholders had only started in their roles following the changes so were unable to comment. However, most had experience in their respective organisations both before and after the changes.

The vast majority of those interviewed felt that the change to EHC plans was positive.

‘EHC plans are fair and sensible and reassures parents as it takes the future into consideration, prior assessments went up to age 16, leaving parents fearful but this has improved. It has a simpler format.’

‘EHC plans are a lot better, it was dire a few years ago. Now we get healthcare plans and they get reviewed annually and are a lot better.’

Although stakeholders acknowledged that parental knowledge regarding the plans had increased and that the number of children with more complex needs may have increased, demand on the services had not increased as a consequence of the introduction of EHC plans.

One negative aspect of the Education, Health and Care Plans which was mentioned was the additional demand the assessments placed on some services.

‘EHC plans are much more administratively heavy than statements.’

21.3.6 Transition to adulthood

Transition to adulthood was identified as an important area by almost all of those interviewed. Many of the stakeholders raised the point that it is a period of anxiety for families and professionals involved. Many stakeholders identified that due to differences in eligibility, many families will see a reduction in services available to them with regards to all aspects of care (social care, health and education).

‘Transition is process based. For parents it is hard as thresholds are very different, they may be used to a certain number of hours of social care from children’s services but will be very different from adults’ services. There’s anxiety for parents when a child is post-18. They are adults but still have a lot of need.’

‘Post full time education a lot of children end up at home and have nothing to do. There’s nothing there. It’s like a cliff edge and a lot of children fall off.’

‘Social care can be tricky for families, particularly around transitions. Children often lose their DLA when they become an adult as there is a much higher threshold. Particularly for young people with moderate learning difficulties, there is very little out there.’

Stakeholders also raised the importance of early planning for the transition period and the fact that it also includes ensuring that young people are supported towards gaining independence.

‘We talk about transition meaning movement from paediatric to adult service. Parents get cross if use transition, so much is preparing for adulthood, which is far wider from transitions from children to adult service. It is holistic, it’s preparing for adult life, it’s far wider.’

‘I think a child with disability, a child with cystic fibrosis, a child with sickle cell, the common thing is that planning needs to start at appropriate time and there is somebody there to bridge that transition and support the child through.’

‘Not all children may go through traditional employment routes, but they may be able to work in community project or do volunteering or apprenticeships to give them real work experience and improve independence and have those experiences.

21.3.7 Advocacy

Advocacy and having support in expressing their views and opinions is an important part of ensuring that the disabled child or young person and their family are receiving adequate support. Stakeholders raised the particular importance of advocacy through assessments and filling out forms.

‘Parents often afraid of social services assessments and want someone with the knowledge of the service to guide them through the process. The parents are sent information prior to the assessment but they find it overwhelming and feel the need to have their hand held.’

‘Really I think it’s about building the capacity of families and parents to advocate on behalf of their children. There could be some training available, why not some sessions for families with children with disabilities enabling them and giving them full info on how to access services eligible for.’

Professionals were also identified as being vital in sign-posting families to the correct services as one of the most frequent barriers to support was families' lack of awareness of what services were available. Stakeholders identified that with such an array of organisations in the local area it was difficult for families to have an awareness of all those that may benefit them.

21.3.8 Housing

The availability of accessible, suitable housing for those with disabilities in both Hackney and the City of London was raised numerous times.

'Housing and the availability of appropriate placements housing in an issue and does sometimes determine the level of health and social care intervention required.'

'Housing is a massive area, the only solution is to build more houses, and more suitable housing. In Hackney it is mostly flats with no gardens on high story buildings. Due to no sense or a reduced sense of danger in the child, a lack of outdoor space and challenging behaviour, housing can be a large source of stress for families.'

21.3.9 Families and carers

The emotional and physical toll of caring for a disabled child on parents, siblings and families with a disabled child was another area which many of the professionals feel needs to be prioritised.

'Supporting these parents and the other siblings, the impact of the disabled child in the family and how they get supported, maybe there is a package we should be putting in place that is standard. It feels to me that some of these parents use up a lot of energy for these children, but what about their own health.'

'It seems clear to me that a lot of the parents suffer in terms of their mental health and they could use support there.'

21.3.10 Charedi Community

Stakeholders which work specifically with the Charedi population and those who work with the entire population including those from the Charedi community were interviewed. Important cultural differences were raised which either effect whether a family from the Charedi will be aware of services available or may influence how suitable a family feel a service is. Although many organisations ensure their staff are aware of cultural differences that may influence the support a family finds appropriate, this is not felt to be universal across all services.

'Parents often have no access to social media, mainstream newspapers etc., so they are not going to get information via these routes.'

'Due to language and cultural barriers, speech therapy can be an issue where English is not the first language. Assessments are therefore incorrect or therapy will not help in English.'

'Parents are very hesitant to see a professional not familiar to community sensitivities for example, that lots of families won't have a computer at home or internet access at home. There are some delicate boundaries.'

'Once a boy is over 13, a woman occupation therapist would be out of the question. The same for psychotherapy.'

‘Hospitals, CAMHS, dentists in Hackney have educated their staff about the community. Social workers are less knowledgeable about the Orthodox Jewish community and their beliefs.’

Another issue that was raised was that many children in the Charedi community attend independent schools. Therapists are funded to provide an in school service within state schools only. Community stakeholders raised that families would be more likely to encourage their child to access therapist support if it were provided within the school environment.

‘Some parents do not accept the degree of disability due to taboo and stigma of having a disabled child. More children would access services if there was less stigma. If therapy is being brought in via the school then parents are more likely to accept, as they parents trust the school.’

21.3.11 City of London

Some of the stakeholders interviewed worked specifically with children and young people living in the City of London, some worked across Hackney alone and some in both local authorities. Stakeholders explained that as the population of children and young people is low in the City of London, the education and social care team are able to get to know the disabled child or young person and their families very well. Other stakeholders, particularly those in health services which are funded by City and Hackney CCG cover both Hackney and the City of London. Due to being able to get to know the families on an individual basis stakeholders, working exclusively in the City of London felt that they were able to meet families’ needs well.

‘City has a very high customer satisfaction rate and need to push families hard to have anything negative to say about the City.’

However, due to the very small number of disabled children living locally and the lack of a local special school in the City of London it was more difficult for families and their disabled child to engage with those going through a similar experience locally.

‘Social isolation is magnified. There aren’t groups of people of the same age with the same challenges in the City. There are no special schools, so no local school community for these children.’

21.3.12 Summary of stakeholder interviews

Although the 24 stakeholders interviewed had varying roles in a diverse variety of organisations there were key themes which were raised by numerous individuals. These were:

- The need to ensure that professionals working with children and young people of all ages are aware of what behaviour or age of meeting developmental milestones should trigger a referral for assessment.
- Clear information for both professionals and families regarding services available for disabled children and young people and the eligibility criteria needed to access each service.
- Ensuring timely information sharing between services to ensure that disabled children, young people and their families are receiving the support they require.
- The process of transition to adult services needs to commence early and transition services need to be focused upon to ensure there is not a cliff edge and loss of support once disabled young people reach the age of 18.
- Housing is an issue for many of the families with a disabled child due to the shortage of accessible and appropriate housing available locally.
- Families and carers need to be supported to ensure that their emotional and mental health is preserved.
- Professionals working with the Charedi community need to be aware of cultural differences which will affect which services are deemed appropriate to families with a disabled child or young person.

22 Methodology and Limitations

22.1 Policy and Evidence Review

22.1.1 Methods

For the purposes of this need’s assessment, relevant government legislation and policies were identified by using the search term ‘disabled children’ individually on the gov.uk website and filtering by organisation. The organisations selected from the government website were the Department for Education, the Department for Work and Pensions, HM Revenue and Customs, the Department of Health, Public Health England, Ofsted and the Office for Disability Issues. The results were subsequently hand-searched. Many results were excluded as they signposted to pertinent pages rather than being legislation or policy themselves. Relevant policy and legislation has been included if applicable to disabled children and young people. National guidelines published by NICE were identified via the nice.org.uk website by hand-searching under the population groups ‘children and young people’, ‘people with learning disabilities’ and ‘people with physical disabilities’. A search of the King’s Fund website was conducted with the search terms ‘disabled’ and ‘children’ separately and then refining to include publications only. A search of the Royal College of General Practitioners, the Royal College of Paediatricians and the Royal College of nursing was also conducted. The search term ‘disab*’ was used to include mentions of disability or disabled. There were one recent non-clinical guideline (ie. not guidelines for medical treatment or therapies) identified when hand-searching the results. A further search of grey literature was performed by using Google to search ‘disabled children’, and also by reviewing pieces referenced in key policy and guidelines.

22.1.2 Limitations

This rapid hand-search review aimed to be comprehensive of all relevant policy and evidence. However, due to limitations on time and resources some relevant documents may have been overlooked. This may affect conclusions reached and recommendations drawn.

22.2 Hackney and City Population data

22.2.1 General Lifestyle Survey

This survey was conducted from 1971 to 2012 the Office of National Statistics and was originally named the General Household Survey. It was re-named the General Lifestyle Survey in 2008 when the Integrated Household Survey was included. [151] It was conducted each year and included the seven chapters: Smoking; Drinking; Households, families and people; Housing and consumer durables; Marriage and cohabitations; Pensions; and General health.

The benefits of the General Lifestyle Survey data is that the data is easily accessible and as it was conducted over 40 years trends over time can be identified. The limitations are that the survey is no longer being conducted so the most recent data is from 2012. Another limitation is that the data is national which makes generalisability to regional level difficult.

22.2.2 Office of National Statistics (Mid-Year Estimates)

The Office of National Statistics produces Mid-Year Estimates of populations and also produces projections for how the population will grow in upcoming years.

The Mid-Year Estimate is produced for each local authority in England. The estimate rounds the number of usual residents of each gender and age group to the nearest 100. The MYE is that it is often used as the official estimate of population size. However, the accuracy of the Mid-Year Estimates is debated as there was an underestimate of 476,000 people between the ONS estimate and the findings of the 2011 census, an under-estimate of 0.9%. [152] This was believed to be due to both a poor response to the 2001 census, and an underestimate of migration. Following this the ONS has aimed to more accurately capture migration statistics to enable for more accurate projections to be calculated.
As ONS estimates and projections are based on current trends, another limitation is that they therefore cannot take into account future changes in migration and government policy that may affect population size. Also the ONS projections do not take housing growth into account which may affect population change. For example if there is no capacity to increase housing it may limit future population growth in an area. This is particularly relevant in London.

22.2.3 Greater London Authority

The Greater London Authority publishes population projections on an annual basis. These are calculated at a ward level as well as a local authority level. The estimates are both age and gender specific. Figures are rounded to the nearest 100.

The benefit of utilising the GLA Strategic Housing Land Availability Assessment (SHLAA) estimate is that it takes future housing development into account, and uses this to estimate net migration into or out of an area. It is widely considered the most accurate protection for London Boroughs. A limitation is that it utilises old ward boundaries at present.

22.2.4 Mayhew Population Count

In 2011 a robust count of Hackney’s population was commissioned to be carried out by Mayhew Harper Associates. [63] The population estimates were derived from a range of administrative databases.[16] The data was then analysed to exclude double counting of individuals and that previous residents were not included.

A limitation was that the analysis depended on the data management of each of the organisations whose database was utilised, therefore it was not possible to verify how current the data was.

22.3 Prevalence of Childhood Disability in Hackney and the City

22.3.1 Thomas Coram Research Institute

The Thomas Coram Research Unit (TCRU) in 2008 requested local authorities to measure the number of disabled children in their population. Each of the 150 Directors of Children’s Services in England were contacted to participate in the survey. Of those contcated115 (77%) completed the survey. Follow-up calls and reminders were sent to non-responders and the team contacted each Local Authority to ensure they had the correct contact details for the Director of Children’s Services. They suggested that figures of children with a Special Educational Need, those receiving Disability Living Allowance and those known to have a disability via any other database be included. The percentage of children with

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[16] GP registers, School Pupil Census data, those liable for Council Tax, households in receipt of Council Tax Benefit or Housing Benefit, the Electoral register, Housing Waiting List, Connexions, Resident Parking Permits, the Local Land and Property Gazetteer, and hospital admissions. [59]

disabilities varied between local authorities, as did the data source utilised by the local authorities[17]. The prevalence of disability in children under 18 based on the questionnaire responses was between 3.0% and 5.4%. [153] Using these figures, the TCRU estimate of disabled children in Hackney in 2016 lies between 1899 and 3418 as shown in Figure 15. Limitations of this data include the fact that many local authorities acknowledged that it was difficult or not possible for them to ensure that children were not double-counted by being present on more than one data source.

Local authorities were asked to rate their confidence that the figure they supplied was an accurate measure of the number of disabled children locally. Of the 109 who answered this question 41% ha low confidence. [153] Only 11% of Local Authorities which responded reported no difficulty in providing a figure of the number of disabled children in their area.

22.3.2 Family Resources Survey- Blackburn et al

The Government utilises the Family Resources Survey to calculate prevalence of disability in the United Kingdom. It is an annual survey that was first launched in 1992. In 2014/15 approximately 20,000 households were interviewed. The survey findings suggests the number of disabled children and adults is rising.

To assess whether a household contains disabled children, participants are asked whether their child has ‘any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more’. [154] If the answer is yes, then they are asked whether their illness or condition reduces their ability to carry out day-to-day activities. Those who answered yes for both questions were counted as having a disability. A study by Blackburn et al in 2010 utilised data from the Family Resources Survey to estimate the prevalence of childhood disability to be 7.3%. [155] This rate was replicated in the most recent 2014/2015 Family Resources Survey. [156] The main limitation of this data source is that it involves self-reporting and the individuals’ subjective view of what whether their health condition reduces their ability to conduct day-to-day activity.

22.3.3 Office of National Statistics- National Child and Maternal Health Intelligence Network

The National Child and Maternal Health Intelligence Network utilises age and gender specific prevalence rates from the document ‘The health of children and young people 2009’ by the Office of National Statistics. [60] [74] Two separate sources of data were used to calculate the rates, the General Household Survey (GHS) and the Family Fund Trust’s (FFT) register of applicants.

General Household Survey

This annual survey captures data on self-reported long-standing illness and disability. Responders were interviewed and the type of illness/disability was recorded and grouped into categories as those in the World Health Organisation International Classification of Diseases (ICD9). Due to long-standing illness and disability being self-reported subjective assessment by the individual completing the form may alter findings.

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[17] Sources included the Children Act Register, Social Care data, SEN school census data, Primary Care Trust health data and other sources.

Family Fund Trust- Register of Applicants – Methods and Limitations

At the time of publication of ‘The health of children and young people’ 2009, the Family Fund Trust provided financial aid to families with severely disabled children aged 16 and under. Applicants supplied the FFT with diagnosis of disability from medical reports, educational assessments or Disability Living Allowance applications. Therefore there was no self-reporting, so the data may be more reliable than that from the General Household Survey. However, the data has other limitations; prevalence is under-reported as it is estimated that only 50-70% of eligible families actually apply for aid. [157] Also, due to the fact that only families with an annual income of less than £20,300 could apply, prevalence rates are further under-estimated as families with higher incomes will not be captured.

22.3.4 Local data

School census data

Completion of the school census is a statutory requirement for schools under the Education Act 1996, therefore schools do not need to obtain parental or pupil consent to provide the information.

Some components on the school census regarding SEND are only captured for state-funded schools within each local authority, such as primary type of need and breakdown of how many pupils with SEND attend primary, secondary or special schools. The data for state-funded schools in the City of London only covers one primary school. This is an important limitation of the data, however as this is the only available school census data specifically for children living in City of London it has still been included.

Although there is only one state-funded school within the City of London the percentage of children with a statement of SEN or EHC plan within the school is almost identical to the average across primary schools in Hackney.

‘The Key’ Hackney’s Voluntary Disability Register Data

Inclusion in the Disability register is currently voluntary, and the Disabled Children’s Service report that the majority included are those who are receiving Short Breaks. There are limitations to the data as of the 753 children and young people on the Register, only 126 had their disability recorded. The classification of disability used varies from those described in section 14 and ethnicity classification varied from those utilised in Census data (for example Jewish has been documented as ethnicity for some individuals). Due to these limitations data from the register was only utilised to comment on ethnicity as it is the only data source that identifies those who report as Jewish. However, it should be noted that for 294 (39%) of those on the register ethnicity was recorded as ‘NULL’.

22.4 Mental Health

22.4.1 Estimate of prevalence

Green et al estimate that 10% of children aged 5 to 16 have a mental health problem. [78] A total of 7,977 children and parents were interviewed in total. Those interviewed were selected from the Child Benefit records and included those from private households living in

England, Scotland and Wales. A sample of postal sectors (426 identified by the ONS), and then a sample of addressed within each postal sector were selected.

Of the 12,294 households initially selected, 10,426 were approached for interview (the remaining 1,085 opted out or had moved). 2,184 households refused interview, leaving a total of 7,977 parents and children interviewed. Of the 7,977 parents and children interviewed 94% (6,236) agreed for their child's teacher to be interviewed also.
The drop-out rate of 35% of those initially selected is a limitation as those who refused to participate in interviews may have had a different rate of mental health problems than those who participated. Also levels of participation varied geographically, with 69% of those in London participating compared to 81% in the South West of England. This may also have affected the data.

22.5 Autistic Spectrum Disorder

22.5.1 Estimate of Prevalence

The Chief Medical Officer's quoted prevalence of 1% of children and young people having autism is based on a study by Baird et al conducted in South London in 2006. [158] A total of 56,946 children aged 9 to 10 were included and those at risk of ASD were identified (1,770 in total). They were identified utilising the list of those with a statement of special educational needs (as even those without identified ASD were felt to be at risk of ASD), and those known to child health and speech and language services reported to have ASD or social/communicative impairments. Those identified were then screened using the validated social communication questionnaire (SCQ). The results were in accordance with those from other studies. A strength of the study was that it used a range of sources to identify those at risk. It also utilised validated assessment tools. A limitation of the study is that those who were not already identified as having ASD had a lower rate of agreement to participate in assessment (56%) compared to those known to have autism (76%), which may have introduced bias.

22.5.2 Local School Census Data

As mentioned within the Autistic Spectrum Disorder chapter, the main limitation of the school census data on ASD is that only primary type of need is recorded. Therefore if a child has multiple needs, for example autism and a learning disability, and their additional needs have a greater impact on their education ASD will not be recorded as their primary type of need. Therefore, school census data is likely to under-estimate the total number of those known to schools with Autistic Spectrum Disorder.

22.6 Oral Health

'Dental public health epidemiology programme, oral health survey of children in special support schools' was a national survey to establish rates of oral health problems in children with special educational needs and disabilities. However, a limitation of this survey is that a total of only 1,415 5-year old children and 3,055 12-year old children had their dental charts completed. The total number of children examined for each disability type varied from 19 (for 5 year olds with a specific learning disability) to 1,014 (12 year old children with moderate learning disabilities). Therefore it is difficult to generalise the data nationally.

22.7 Focus Groups

The methodology of the focus group and analysis of the data is described in chapter 20. The advantages of focus groups are that they provide in-depth qualitative data about individual experiences which it is difficult to capture via other methods. Those participating may have been more likely to share their experiences knowing that the other participants had shared similar experiences and difficulties. Also as the discussion was audio-taped and transcribed verbatim others can return to the original unanalysed data and conduct their own analysis.

Limitations of focus groups are that the sample size is small so it is difficult to generalise to the population in question, particularly as participation is self-selected. Also another disadvantage of utilising focus groups is that outspoken individuals can dominate the conversation unless the facilitator is well-trained and able to moderate. [159]

22.8 Stakeholder Interviews

The methodology and analysis of the stakeholder interviews is described in chapter 21. An advantage of the stakeholder interviews is that it included professionals from varying organisations involved in the care of disabled children and young people from health, education and social care. It also included professionals from both Hackney and the City of London as well as professionals who work with those from both boroughs.

A limitation of the interviews are that those involved were asked to describe their personal experiences in working with those with disabilities, therefore their views may not represent those of all those within their organisation.

23 Recommendations

The recommendations in this chapter are based on recommendations from policy and literature, conclusions from data analysis and feedback from parents and stakeholders. These recommendations are in addition to those outlined in the 0-5 and 5-19 year old Health Needs Assessments.

23.1 Identification and diagnosis of disability

- All NHS funded services in England should adopt the SNOMED classification system by 2020. [20] Ensure that this process is already underway in Hackney and the City of London.
- Ensure that all those working with children and young people in health, education and social care have adequate training in identifying special educational needs and disability and information on how and where to refer children and young people for further assessment. There is a high proportion of young people in the Youth Justice Service with undiagnosed SEN and/or speech and language difficulties – these are identified when the Service starts working with the young person and appropriate support provided through the Youth Justice Service.
- Ensure that there is accessible, jargon free information for parents locally who may have concerns their child has a disability and what steps they can take to access assessment and support. This information should be available online via the Local Offer, in leaflets at children's centres and GP surgeries, and via appropriate signposting from professionals.
- Set up a multi-disciplinary Task and Finish group including key partners from education, health and social care to discuss the most appropriate organisation to hold a database on disability in children and young people. This data can then be utilised to accurately comment on prevalence and inform service planning.

23.2 Mental Health

- Continue the long-term development of early intervention services within CAMHS to help prevent children and young people reaching crisis point and avoid longer term intervention in adulthood. [82]
- Children and young people with learning disabilities, Autistic Spectrum Disorders and chronic health conditions should be assessed for mental health problems at time of diagnosis and at a minimum of annually.
- Support secondary schools in meeting the NICE guidelines with regards to promoting social and emotional wellbeing by ensuring there is access to pastoral care and specialist services.
- Consider identification of mental health problems to be included within the Year 6/7 transition to secondary school health review. For those identified with mental health problems ensure appropriate referral/signposting and accurate data recording.
- Investigate the specific level of need in the local Charedi, Kurdish and Turkish communities. Currently it is not possible to identify whether these populations are accessing mental health services, based on stakeholder interviews local services may not be deemed culturally appropriate for these populations.

23.3 Autism

- Continue to diagnose and support those with autism in line with the National Institute of Clinical Excellence guidelines.
- It is estimated that nationally 40% of those with autism are undiagnosed. Professionals within health and education working with children and young people should be trained in assessing basic development and have an awareness of signs of autism and knowledge of where to refer those who require further assessment.
- Ensure that professionals continue to be aware that autism may present differently in females and social features may be more subtle.

23.4 Obesity

- Utilise a whole-family holistic approach in encouraging healthy eating, obesity prevention and obesity management.
- Identify those pupils within special schools with obesity and engage the school and their family in management.
- Encourage referral to obesity management services. Ensure professionals referring to the service are aware that the threshold is lower for those with learning disabilities or complex needs.

23.5 Oral Health

- Ensure that all professionals involved in supporting disabled children are aware of the importance of oral health, and aware of what specialist services are available for those with disabilities.
- Encourage all local special schools to participate in the Public Health supervised tooth-brushing programme.
- Encourage parents take their child for regular dental checks and to participate in the local Public Health fluoride varnish programme which has been proven to be safe and highly effective in reducing decay.
- Consider establishing a register of local dentists to establish database on dental attendance for those with disabilities.
- Consider gaining local data on accessibility of local dental services for those with disabilities via mystery shopping.

23.6 Respiratory Health

- Ensure that those with asthma have a written ‘action plan’ as recommended by NICE to ensure they are aware of how to recognise and manage an acute worsening of symptoms. Primary care to audit proportion of children and young people an asthma action plan. Ensure that appropriate members of school staff and school-based health services have access to asthma action plans.
- Primary care to conduct an audit into the uptake of annual influenza vaccination in children and young people with asthma.
- Continue to implement measures to reduce air pollution as outlined in the Mayor of London’s ‘Clearing the air’ strategy. Continue to monitor data on exacerbations, diagnoses or hospitalisations related to asthma to assess whether this is affected by changes in air pollution levels locally.

23.7 Sexual Health

- As outlined by the Department of Education and Employment, it should be ensured that those with learning disabilities have sexual and relationship education appropriate to their level of understanding.
- Aim to collect data on disability and use of local sexual health services to guide local service planning.

23.8 Education

- Ensure that children and young people who have prolonged absence due to illness or hospitalisation are provided with schoolwork and support to ensure they do not fall behind.
- Consider conducting qualitative research in conjunction with schools to understand why pupils with Special Educational Needs and Disabilities in Hackney have higher rates of fixed period and permanent exclusion than the England average, and the third highest of its statistical peers.

23.9 Safeguarding

- Ensure that all professionals supporting disabled children are aware that those with disabilities are particularly vulnerable to abuse and neglect. Ensure professionals are adequately trained in how to recognise signs of abuse and neglect. Safeguarding training should be refreshed every 3 years and records of training retained by the organisation.
- Ensure that all new services commissioned meet the City and Hackney Safeguarding Children Board's Minimum Expectations.
- Consider having a designated lead for safeguarding disabled children within the City and Hackney Safeguarding Children Board as per the Department for Children, Schools and Families 'Safeguarding Disabled Children Practice Guideline'. [160]

23.10 Finances

- Ensure that families are signposted to services which can assist in benefits applications, such as City and Hackney Carers Centre.
- Ensure that information regarding benefits and eligibility for benefits is easily understandable and available in locally spoken languages. Ensure professionals supporting families with disabled children and young people are aware of where this information can be found to allow appropriate signposting.
- Support families to access suitable childcare to allow parents who wish to go to work the opportunity to do so, knowing their child is appropriately cared for. Just as nurseries listed on the Hackney Local Offer describe what services/input are available for those with disabilities, local childminders listed on the Local Offer website should be encouraged to list their level of experience and any relevant qualifications held with regards to caring for disabled children.

23.11 Transitions

- Children and Young People's and SEND services to record transition data in an accurate, secure manner ensuring all that relevant demographic data is captured.

- Ensure that both children’s (CYPS and SEND) and adult’s social care teams share data regarding transition and outcomes of referrals and assessments.
- Aim to improve opportunities with regards to paid work, volunteering and apprenticeships for young people with disabilities.

23.12 Other

- Consider conducting a local carer’s needs assessment looking at parents and siblings of disabled children and young people, child carer~~’~~s, and adult carers.
- Professionals supporting families of disabled children and young people to ensure that the emotional wellbeing of non-disabled siblings is assessed and if necessary they are referred to appropriate services.
- Aim to ensure that new housing developments include affordable housing and that this is accessible and appropriate for those with disabilities.
- Ensure that children and young people with disabilities, their families and carers are involved throughout the commissioning cycle.
- Explore options regarding improving data sharing between healthcare, education and social care services by exploring possibilities for shared information systems.
- Encourage those with disabilities and their families to provide feedback on the accessibility of local services (mainstream and specialist) via organisations such as Healthwatch.

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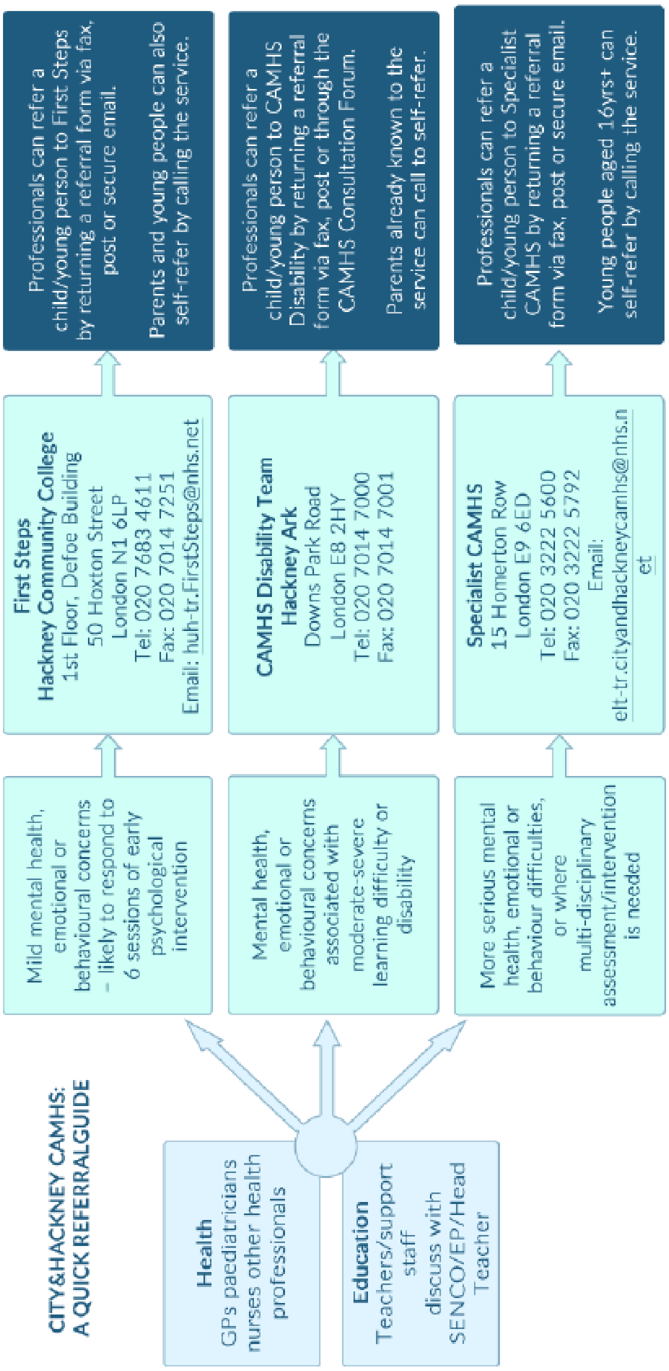
25 Table of Figures

26 Appendices

26.1 Appendix 1- CAMHS referral pathway [161]



CITY&HACKNEY CAMHS: A QUICK REFERRALGUIDE

Health
GPs paediatricians nurses other health professionals

Education
Teachers/support staff
discuss with SENCO/EP/Head Teacher

Mild mental health, emotional or behavioural concerns - likely to respond to 6 sessions of early psychological intervention

First Steps
Hackney Community College
1st Floor, Defoe Building
50 Hoxton Street
London N1 6LP
Tel: 020 7683 4611
Fax: 020 7014 7251
Email: huh-tr.FirstSteps@nhs.net

Professionals can refer a child/young person to First Steps by returning a referral form via fax, post or secure email.

Parents and young people can also self-refer by calling the service.

Mental health, emotional or behavioural concerns associated with moderate-severe learning difficulty or disability

CAMHS Disability Team
Hackney Ark
Downs Park Road
London E8 2HY
Tel: 020 7014 7000
Fax: 020 7014 7001

Professionals can refer a child/young person to CAMHS Disability by returning a referral form via fax, post or through the CAMHS Consultation Forum.

Parents already known to the service can call to self-refer.

More serious mental health, emotional or behaviour difficulties, or where multi-disciplinary assessment/intervention is needed

Specialist CAMHS
15 Homerton Row
London E9 6ED
Tel: 020 3222 5600
Fax: 020 3222 5792
Email:
elt-tr.cityandhackneycamhs@nhs.net

Professionals can refer a child/young person to Specialist CAMHS by returning a referral form via fax, post or secure email.

Young people aged 16yrs+ can self-refer by calling the service.

26.2 Appendix 2- Read Codes used to identify those with Autistic Spectrum Disorder on GP records

- Eu84.|00FyR|C|[X]Pervasive developmental disorders
- Eu840|00FyS|C|[X]Childhood autism
- Eu841|00FyX|C|[X]Atypical autism

- Eu842|00Fya|C|[X]Rett's syndrome
- Eu843|00Fyb|C|[X]Other childhood disintegrative disorder
- Eu844|00Fyg|C|[X]Overactive disorder associated with mental retardation and stereotyped movements
- Eu845|00Fyh|C|[X]Asperger's syndrome
- Eu846|00Fyk|C|Pathological demand avoidance
- Eu84y|00Fym|C|[X]Other pervasive developmental disorders
- Eu84z|00Fyn|C|[X]Pervasive developmental disorder, unspecified
- E140.|00FZb|C|Infantile autism
- E1400|00FZf|C|Active infantile autism
- E1401|00FZg|C|Residual infantile autism
- E140z|00FZh|C|Infantile autism NOS

26.3 Appendix 3- Information sent to parents regarding the focus group.

Disabled Children's Needs Assessment- Focus Group

What is the Disabled Children's Needs Assessment?

The aim is to describe the needs of disabled children living in Hackney and the City of London. It is being written by the Public Health team.
This focus group is to let us get feedback from parents and carers of disabled children and young people about certain local services. We're interested in what you think and comments on your past experiences of services such as mental health (CAMHS), moving to adult services etc. This is not a piece of commissioning work.

How will the focus group work?

I will be recording the group so that everyone's opinions can be noted, but we will not use anyone's names. Any quotes or comments used in the assessment will be anonymous.

To help everyone feel comfortable giving their thoughts, please do not repeat what other focus group members have said outside the room.

If a question or topic is not clear, please let me know.

If you do not feel comfortable discussing a topic, feel free not to answer or let me know.

The group will last around one and a half to two hours (including introductions).

Refreshments will be provided.

Many thanks,

Public Health Team