JSNA
Joint Strategic Needs Assessment

Children and Young People with Special Educational Needs and Disabilities

Joint Strategic Needs Assessment (JSNA) Report

Royal Borough of Kensington and Chelsea

West London Clinical Commissioning Group

This report

This needs assessment supports the development of a Joint Local Authority and Clinical Commissioning Group (CCG) commissioning strategy for children and young people with complex needs.

It specifically aims to describe:

- the prevalence, trends and characteristics of special educational needs and disabilities in the borough, compared to the national picture
- the current service provision
- identify gaps in services and areas of unmet need

Data was collected from a number of sources including local data provided by stakeholders and providers.

Authors and contributors

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Acknowledgements

We would like to thank the task and finish group, everyone who contributed in workshops, partners who provided data and reviewed the JSNA, and the JSNA Steering group.

CONTENTS

1   Executive summary

A child or young person is defined as having a special educational need if they have a learning difficulty or disability which requires special educational provision to be made for them. Life chances for children with SEN and/or a disability can be poor compared to the general population, and they may find it harder to make the transition from childhood to adult life, form successful friendships and relationships, maintain their independence and are more likely to have poor health and wellbeing outcomes. Young people with SEN are also less likely to be in education, training and employment, which further affects their adult life.

The needs of children and young people with SEN or a disability are complex and varied, and requires daily support from a wide range of professionals and agencies. Their families and carers experience high levels of stress as they juggle the daily requirements of ensuring support for their child with the demands of everyday family life, and also require help and support.

Kensington and Chelsea has high ambitions for all children and young people to have a good start in life, including those with special educational needs and disabilities (SEND). Children and young people, including those with the most complex needs should have access to good local provision and every opportunity to achieve good outcomes, whether this be education, employment, independent living, participation in their community or being as healthy as possible.

The primary purpose of this needs assessment is to inform the development of the joint Local Authority and Clinical Commissioning Group SEND Strategy for the Bi-borough. It draws on data and evidence drawn from a range of sources, including the views of parents and professionals working in the field, to describe a picture of SEND need and service provision across Kensington and Chelsea. Where gaps and challenges have been identified, recommendations have been made which can be taken forward in the local strategy.

1.1   Main findings

The following points provide an overview of the SEND population in Kensington and Chelsea. For further information on specific conditions please visit the relevant chapter which describes in brief what we know nationally and locally.

- ➢ 1,628 pupils in Kensington and Chelsea schools have a special educational need (approx. 13% of the school population)

- ➢ 4,898 children and young people in the West London CCG boundary are known to their GP to have a SEND need (a higher figure than above due to including young people up to the age of 25, including young people with mental health diagnosis post school years, possibly including children and young people who go to private schools, and the CCG boundary also including North Westminster, November 2017)

- ➢ 190 children between the age of 2-4 are known to early years' settings with special educational needs

- ➢ There are more boys than girls with an EHC plan and SEN support, in line with London and UK

- Poverty and deprivation; lifestyle factors such as smoking and consuming alcohol during pregnancy; low birth weight; parental stress; and family breakdown all contribute to the likelihood of developing a special educational need.

- Children and young people with SEND do less well on long term outcomes e.g. lower academic performance; being in education, employment or training; or being in the criminal justice system.

- Speech, language and communication needs is the most common reason for SEN support in primary school children in Kensington and Chelsea (29% of state funded primary school pupils with SEN)

- Social, emotional and mental health needs are the most common reason for SEN support in secondary school children in Kensington and Chelsea (18% of state-funded secondary school pupils with SEN).

- Kensington and Chelsea has the same participation rates in education or training amongst 16-17 year olds with SEND as the national average (87%) but 5% less than the inner London average (92%)

- Only 51% of Education, Health and Care Plan assessments in Kensington and Chelsea were conducted within the statutory time of 20 weeks in 2017, however this is an improvement on 33% in 2016 which compared to 48% across London

- NICE guidelines state the autism diagnostic assessment should start within three months of the referral to the autism team (NICE, 2011 (updated 2017)). Waiting times for referral to diagnosis of ASD for 4.5 year olds and older were over a year in 2017/18 in the south of Kensington and Chelsea, and 41 weeks from referral to diagnosis in north Kensington and Chelsea.

1.2   Key messages

This report draws together population analysis, policy, research and professional and service user views to inform an analysis of gaps, challenges and potential opportunities, which should be considered in the development and implementation of local strategy. These are arranged by theme below.

Theme	Gaps, challenges and opportunities
Early identification, diagnosis and post diagnosis support	• Waiting for a diagnosis of ASD can be a challenging and stressful time for children and young people and their families. It is important that they have appropriate and timely support at this critical time. Whilst children and young people can access therapy services whilst waiting for a diagnosis, support and information for parents could be more transparent and consideration given to a more tailored offer of support. • There needs to be clear and accessible information on the ASD diagnosis, and on post diagnosis support and services available to service users and their families. Information should highlight what services are available, how to access them, and a 'who's who' for the ASD pathway. Further development of Autism friendly pages on the boroughs Local Offer may be required. • Continued engagement between the local authority, schools, the CCG and health partners is necessary at both a strategic and operational level in order to address capacity issues and ensure timely identification and appropriate post diagnosis support is in place for children and their families
Information and signposting	• The Local Offer, in particular reference to autism, needs to be reviewed and updated in consultation with parent/carers and key stakeholders to ensure that evidenced needs are met and that more children and young people with autism are living, educated, working and actively engaged in their local community A best practice example includes Surrey's Local Offer that tailors support to those who are pre diagnosis and those who are post diagnosis. • All staff working with children and young people and their families in the local area should be aware of the local offer website and be able to signpost families to the support available
Service provision	• Population turnover, or 'churn', in and out of the borough necessitates effective planning for a seamless transfer of children and young people with SEND into their new host borough. In 2016, 11% of the population of Kensington and Chelsea left the borough (including 884 aged 0-24) and 10% of the population moved in (including 717 aged 0-24) • Schools and colleges need to improve the quality, accessibility and transparency of what the 'offer' is in each educational setting. This could be addressed through an audit on SEN Information Reports;

	identification of best practice; and co-production of parent friendly guide to what they can expect for a child or young person on SEN Support or with EHC Plan • Forecasts show an increasing number of children with SEND, and specifically ASD, LD, SEMH and SLCN. It is important that future planning; capital funding and workforce development activities capacity build existing services to accommodate the projected growth in the cohort(s)

Transition	• Among some parents of children and young people with SEND there is uncertainty and a lack of confidence over the transition process to adulthood. Further joint working between Children's Services, Adult Social Care, Health, the voluntary and community sector and local businesses is required to simplify processes and communication with families and to promote pathways to post 16 education; employment; supported/independent living and accessing the local community via the Bi-Borough PFA governance
	
	• Pathways post 16 are not focused sufficiently well on preparing those on SEN Support and those with EHC Plans for adult life. Further work, led by the PFA stakeholders, could develop pathways for specific cohorts of young people (post 16) with SEND:
	
	    • High Functioning Autism
	    • Complex needs and requiring medical interventions
	    • SLCN
	    • PMLD

Wider impact	• Children and young people with a special educational need and/or complex needs are more likely to have poor mental health and wellbeing. Early intervention and prevention are key to improving the emotional and mental wellbeing of this cohort. Local strategies should consider how the mental health and wellbeing of children and young people with SEN can be promoted. • Children and young people with SLCN are less likely to progress into college education, more likely to experience unemployment, and more likely to have contact with the youth justice system. A Local Authority led speech and language Task & Finish Group has been created which aims to establish a SaLT pathway, it is recommended the group address these challenges.

Further research	• There is a higher percentage of children with specific learning difficulties in comparison to the national average. More detailed research and analysis on the needs of this group is required in order to inform service design and delivery
	• National data suggests children and young people with SEND have adverse outcomes in a wide range of life situations, for example autistic people are at higher risk of depression and anxiety and ADHD is associated with higher rates of substance misuse and sexual risk. More research is required to understand local prevalence.
	• A comprehensive and combined SEND database, across education, health and care, would help plan for the future

2   Introduction

The Special Educational Needs and Disability (SEND) Code of Practice (Department for Education and Department of Health, 2015), states that a Joint Strategic Needs Assessment must be produced to analyse the needs of the local community. This JSNA will consider 0-25 year olds living in the Kensington and Chelsea, going to school in Kensington and Chelsea and those registered with a GP in West London CCG, 22.8% of whom live in the City of Westminster. The JSNA will shape the joint Health and Local Authority commissioning strategy for children and young people with complex needs aged 0-25, which will inform the re-commissioning of services and redesign of pathways.

Definition

The Children and Families Act states a child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to made for him or her. This is defined as if he or she has significantly greater difficulty learning than the majority of others of the same age, or if he or she has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in schools or mainstream post-16 institutions.

The Act has replaced the Statement of Educational Needs with the Education, Health and Care Plan (ECHP). Since 1st September 2014, all new statutory assessments have been made under the new system. Children with existing statements are in the process of being transferred to EHCPs over the course of a three-year transition (Department of Health, 2014).

2.1   Summary of legislation and guidance

Duties under the Children and Families Act 2014

A **local authority** in England must exercise its functions to identify all children and young people who have or may have special educational needs or disability (C&FA S.22)

Local authorities are responsible for integrating education, training, healthcare, and social care where this would promote the wellbeing of young people with SEND. This addresses a range of subjects such as their mental and physical health, personal relationships, recreational opportunities, contribution to society and more.

Local authorities and partner commissioning bodies are also required to put in place joint commissioning arrangements in order to plan and jointly commission the education, health and care provision for disabled children and young people with SEN.

If a **health body** (such as a Clinical Commissioning Group (CCG) or NHS Trust) informs the opinion that a child has (or probably has) special educational needs or a disability they must:
- Inform the child's parents and provide an opportunity to discuss
- Bring their opinion to the attention of the Local Authority (C&FA S.23)

As part of the Children and Families Act 2014, the support for children with SEN was simplified to two levels:

- SEN Support (replacing 'School Action' and 'School Action Plus'). The majority of children and young people with SEN will have their needs met by this non-statutory SEN support service in schools.
- Education, Health and Care (EHC) Plan for children and young people up to 25 years who require more support (replacing 'Statements' of SEN). These identify the educational, health and social needs and define the additional support required to meet those needs.

Children and young people can receive SEN Support or support provided through an Education, Health and Care Plan in an early years setting, a mainstream primary or secondary school, a college, in a home school setting, or in a special school. Many providers do not differentiate by the type of need of children and young people with SEND, but by the level of intervention that is needed. Special schools have a more complex cohort than ever before, and mainstream schools are working with a higher number of complex needs children.

Duties under the NHS Act 2006

Under the NHS Act 2006, the Clinical Commissioning Groups have a duty to commission services to meet the needs of the population for which they are responsible, to a reasonable extent.

Duties under the Care Act 2014 and Transition

For children approaching adulthood, the Care Act 2014 requires local authorities to assess the needs of children likely to need care and support after turning 18 (as is very likely in the case of SEND young people) (CA S.58). NICE offers guidance on the transition from children's to adults' services for young people using health or social care services (NICE, 2016).

Preparation for transition should start early. The SEND Code of Practice says, "When a child is very young, or SEN is first identified, families need to know that the great majority of children and young people with SEN or disabilities, with the right support, can find work, be supported to live independently, and participate in their community. Health workers, social workers, early years' providers and schools should encourage these ambitions right from the start."

When a young person is under the care of a paediatrician, health professionals must work with the young person to develop a transition plan, which identifies who will take the lead in co-ordinating care and referrals to other services. The young person should know who is taking the lead and how to contact them. If the young person has an EHC plan, the CCG and local authority must cooperate to meet the outcomes in the EHC plan.

2.2   Local strategies

Locally, the North West London Sustainability and Transformation Plan (STP) intends to support those with SEND to adopt healthier lifestyles, and to implement annual health checks and individualised healthcare plans. The STP also plans to deliver the North West London Transforming Care Plan for people with learning disabilities, autism and challenging behaviour, and to provide tailored crisis support for this group.

The [Joint Health and Wellbeing Strategy](#) (2017-22) has given precedence to fulfilling the requirements of the Children and Families Act. One of the priorities is to improve outcomes for children and young people. These include transition into adulthood, and addressing mental and physical health and wellbeing holistically. One such outcome addresses access to specialist services where appropriate. Another is meant to ensure that educators are trained to recognise and support the mental and physical health issues of the children they care for.

3 Overview of SEND population

For information on the general population context please visit the JSNA Highlight Report for Kensington and Chelsea.

- There are 42,736 children and young people aged 0-25 in Kensington and Chelsea[1]
- There are 4,898 children and young people known to their GP within the West London CCG boundary with SEND needs including: autism, learning disabilities, physical disabilities, sensory impairments, mental health, asthma, epilepsy and diabetes (November 2017)[2]
- There are 198 2, 3 and 4 year olds either with an EHC plan or receiving SEN support (4.7% of 2 year olds, 0.9% of 3&4 year olds with an EHC plan and 6.3% of 3&4 year olds receiving SEN support who are benefitting from funded early education).
- 12% of the school population (primary and secondary) have special educational needs
- There are 504 children and young people for whom the local authority maintains a statement of SEN, or EHC Plan.

3.1.1 Gender

➢ There are significantly more boys than girls with EHC plans and SEN support in Kensington and Chelsea, as is the case across London and the UK

Figure 1: EHC plans and SEN support of school age by gender
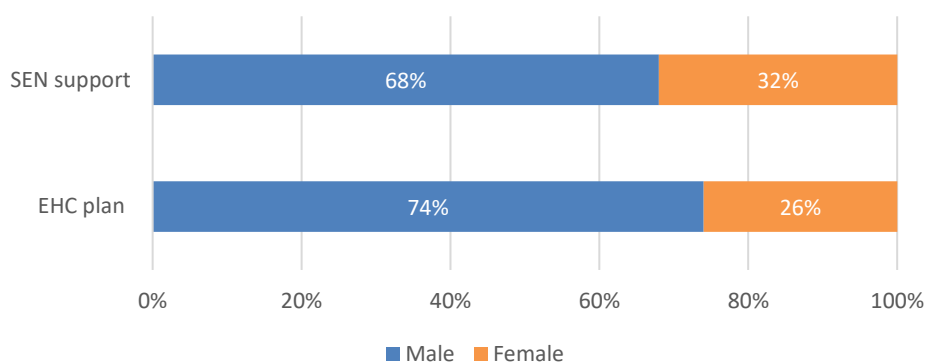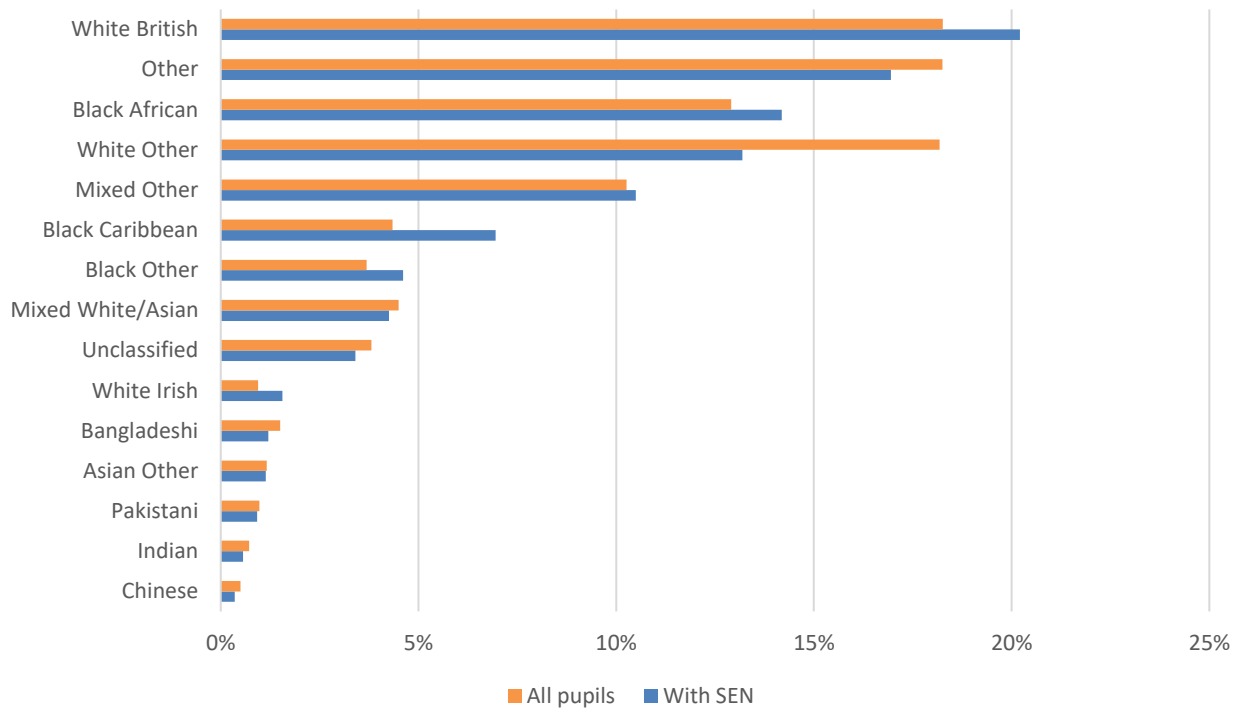

Source: School census, January 2017

3.1.2 Ethnicity

There is a higher proportion of White British, Black African and Black Caribbean pupils with SEN in Kensington and Chelsea compared to the school population as a whole.

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[1] Mid-year estimates 2016 (published June 2017)
[2] System One and QOF data from West London CCG

Figure 2: Proportion of pupils with SEN by ethnicity, compared to proportion of all pupils by ethnicity

Source: School census 2017

3.1.3 Deprivation

Poverty is both a cause and effect of Special Educational Needs and Disabilities (Shaw, Bernardes, Trethewey, & Menzies, 2016). Children with SEND from low-income families face multiple disadvantages and increased vulnerability; they are less likely to receive support or effective interventions for their needs, partly because their parents are less likely to be successful in seeking help, and more likely to leave school with low attainment and therefore have diminished chances of finding well-paid work as adults. Families of children with SEND are more likely to move into poverty, for example as a result of the costs and/or stress associated with their child's SEND status (Parsons & Platt, 2013).

Factors associated with poverty such as smoking and consuming alcohol during pregnancy, low birth weight, parental stress and family breakdown can also contribute to the likelihood of a child developing certain types of SEND (Anders, et al., 2011) (Parsons & Platt, 2013).

Kensington and Chelsea is characterized by areas of high deprivation and areas of great wealth, with inequality of health outcomes. Children and young people with complex needs are more likely to live in deprived areas, in particular the north of the borough and areas of social housing.

Figure 3: The links between SEND and poverty
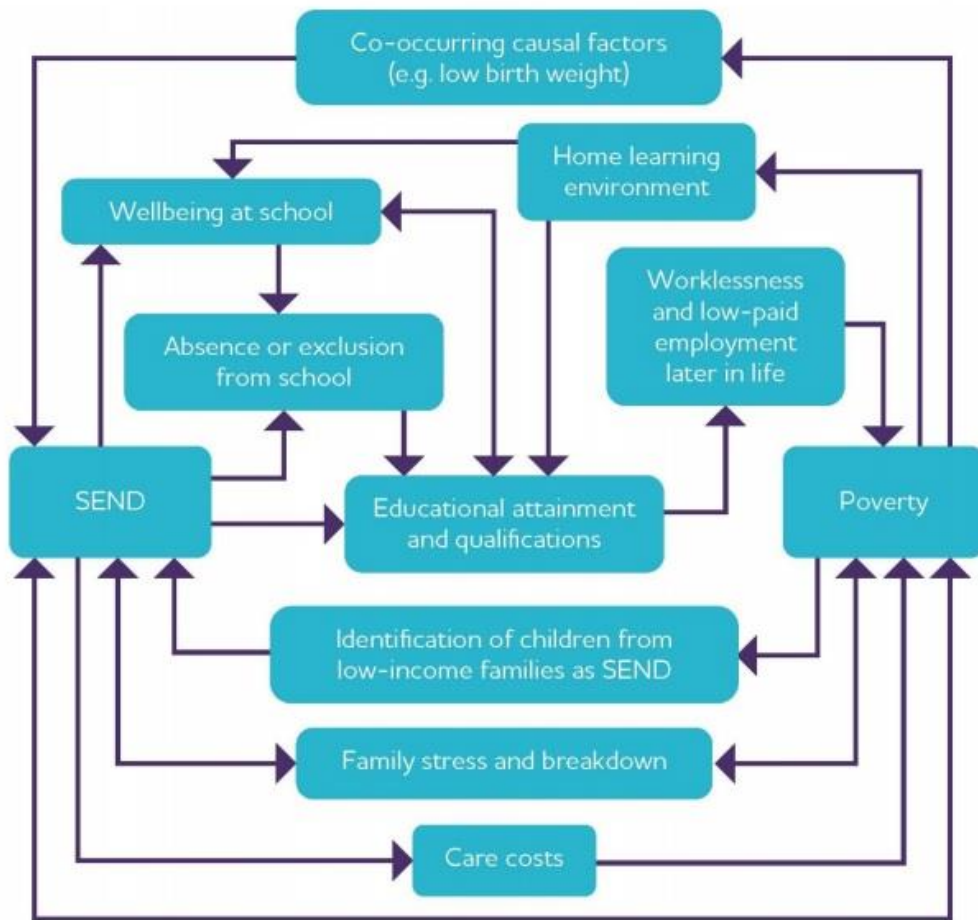
Source: Joseph Rowntree Foundation report, February 2016

4 Special educational needs in education

4.1 Early years

Early years education plays a pivotal role in both preventing SEN and preparing children who have SEND to be ready for school and therefore later educational attainment (Shaw, Bernardes, Trethewey, & Menzies, 2016).

4.1.1 What do we know locally?

Health Visiting and Maternity Care: All children benefit from new born ante-natal screening with health visiting picking up blood spot tests for new arrivals. The tests identify nine conditions at a very early stage. All families are offered the five mandated health visitor contacts, with vulnerable families offered more intensive support from health visitors as part of the Healthy Child Programme. At the two-year check, 100% of children seen receive an Ages and Stages Questionnaire (ASQ) assessment for child development. Children with suspected development delay then receive an ASQ SE2 assessment to assess further development needs and onward referrals to specialist services.

2 year olds: There are 190 children aged 2 that are benefitting from funded early education in Kensington and Chelsea. Of these, none have an EHC plan and 9 are receiving SEN support (4.7%). Whilst Kensington and Chelsea have no children with an EHC plan, the percentage of children receiving SEN support is slightly higher than the inner London (3.7%) and national (2.7%) average.

3 & 4 year olds: There are 2,610 children aged 3 and 4 that are benefitting from funded early education in Kensington and Chelsea. Of these, 24 have an EHC plan (0.9%) and 165 are receiving SEN support (6.3%). Kensington and Chelsea are in line with inner London with both EHC plans and SEN support and slightly higher than the national average.

Figure 4: Percentage of 2, 3 and 4 year old children benefitting from funded early education, with special educational needs, 2017
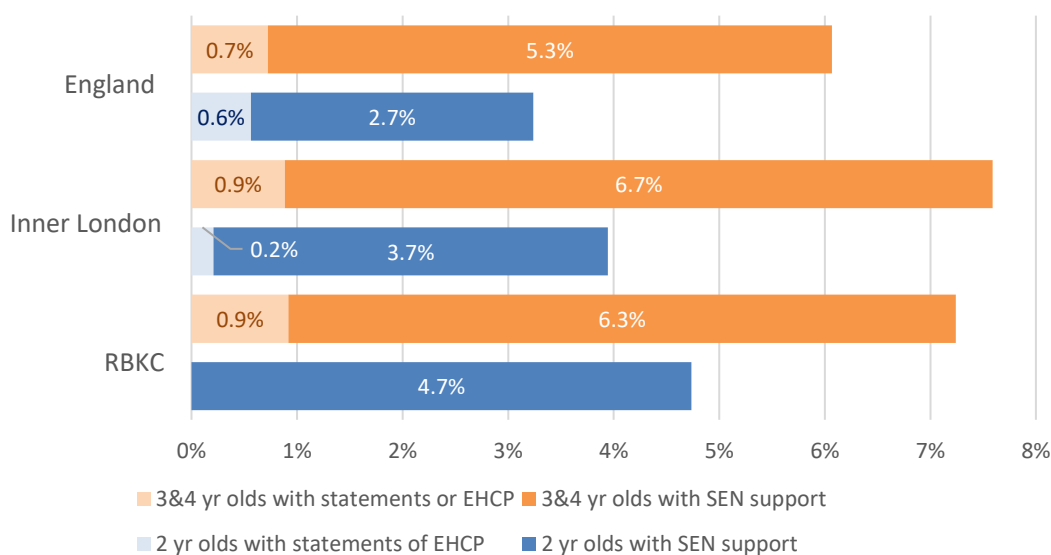
Source: **DfE Statistics - Provision for children under 5 years of age in England**

4.1.2   Early years level of development

The percentage of pupils with SEN in early years' foundation stage reaching a good level of development is 8% below that of the national average in 2017, and down by 4% from 2016.

Figure 5: Percentage of early years' pupils reaching a good level of development
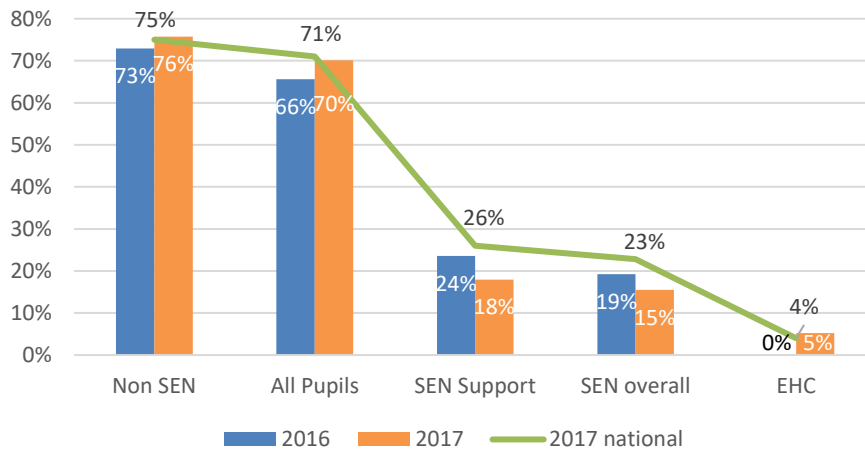
4.1.3   Early years referrals for speech and language support

Speech and language support is the most likely need in early years. The majority of referrals for early years support in speech and language are made by health visitors (41% of referrals), followed by nursery schools (26% of referrals).

Figure 6: Number of referrals by referrer
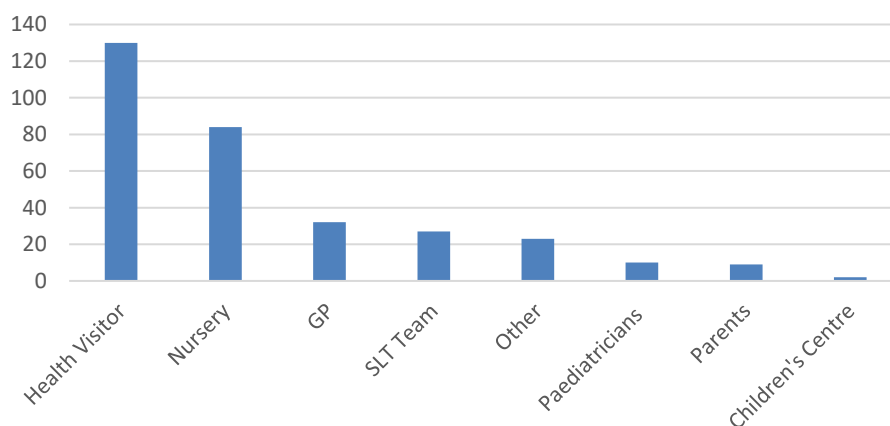
Of the cases referred between September 2017 and February 2018, 42% of cases were for complex needs (673 children), 34% were due to developmental delay (539 children), and 23% were for a disorder (372 children).

Figure 7: Percentage of cases by type
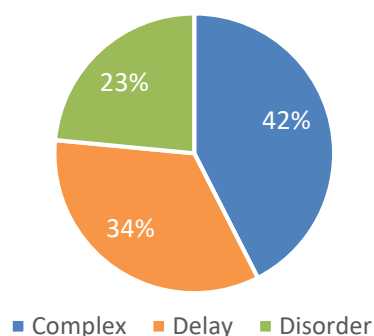
Legend: ■ Complex ■ Delay ■ Disorder

4.1.4   Waiting times for assessment and treatment for speech and language support

Since April 2017, only 86% of referrals for early years' speech and language therapy were seen for assessment within the target 8 weeks.

Only 77% of cases waiting for treatment received treatment within the target 12 week waiting period.

Table: Waiting times for assessment and treatment

Waiting time	Target	Percentage within target April '17-February '18
For assessment	8 weeks	**86%** of referrals seen within 8 weeks
For treatment	12 weeks	**77%** receiving treatment within 12 weeks

4.2   School years

The best school or educational setting for a child depends on their needs. Most children with SEND, including those with Education, Health and Care Plans, will attend a mainstream school, college or university. Children with more specialist needs may benefit from a more specialist setting.

4.2.1   How many residents have SEND?

The number of children and young people who live in the borough and for whom the local authority maintains a statement of SEN, or an EHC plan is 504; 1% of children and young people with statements or EHC plans are educated elsewhere.

Of those maintained by the local authority, the majority are placed in local authority maintained mainstream schools (36%), local authority maintained special schools (22%), and mainstream school academies (20%).

Figure 8: Placement of children and young people with a statement or EHC plan by local authority

Legend: ■ England ■ Inner London ■ RBKC
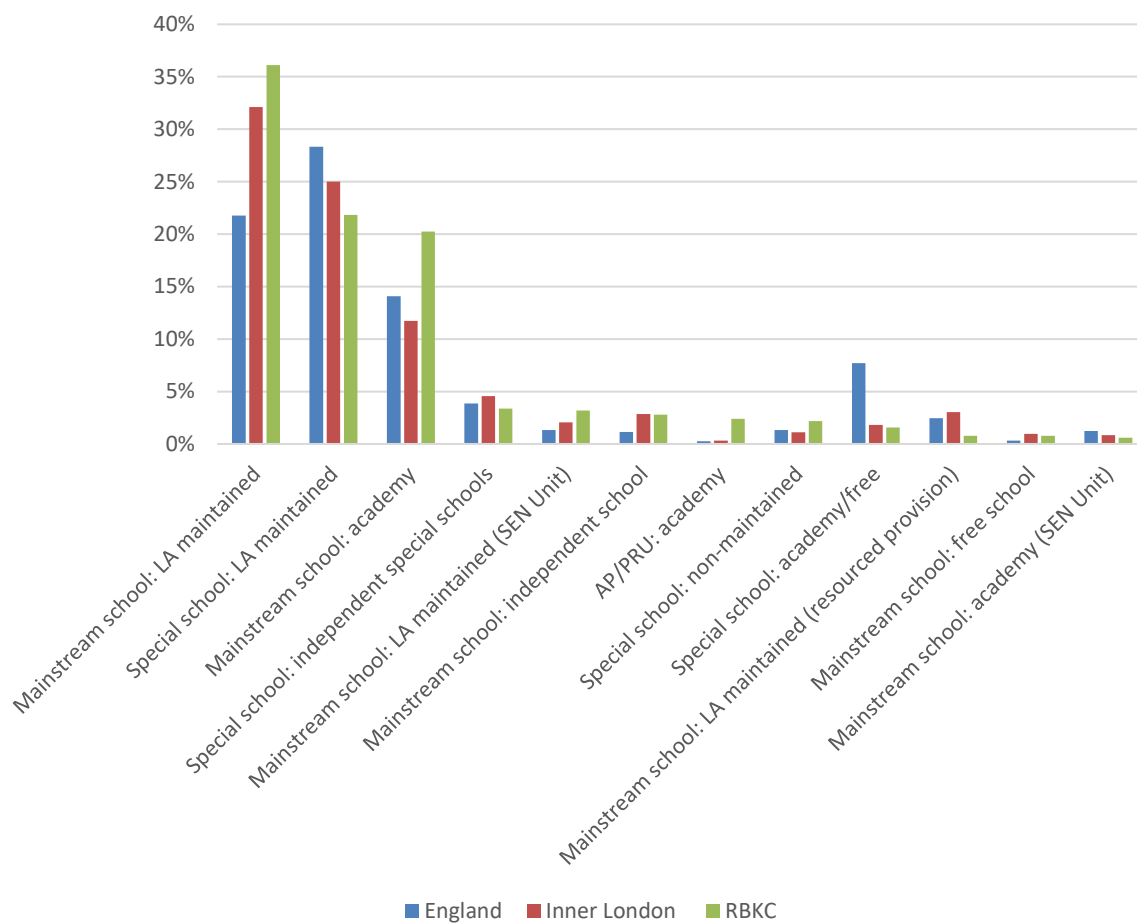
Source: Special educational needs and disability (SEND) and high needs (January 2017)

Within inner London there are high levels of borough migration for school. In 2017 in Kensington and Chelsea there were:

➢ 8,201 pupils living in the borough, but 11,035 pupils attending schools maintained by the borough[3].
  o 39% of pupils attending schools maintained by Kensington and Chelsea live in a different borough.
  o 18% of pupils who live in Kensington and Chelsea attend a school maintained by another borough.
➢ In 2015 it was found that 52% of pupils who go to school in the borough, attend a private school[4]. These pupils are out of scope of the school data (DfE).

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[3] Department for Education. School pupils and their characteristics, January 2017: Table 13: Local Authority cross border movement by national curriculum year group of state-funded school pupils resident in England
[4] GLA London Datastore: Schools and pupils, type, school, borough, 2015

Therefore, the data sourced from schools used in this JSNA demonstrate all pupils attending school in the borough, regardless of where they live.

In 2017 an external review of Kensington and Chelsea's spend on children and young people with High Needs was undertaken, which explains funding in detail, including pupils from outside the borough[5].

4.2.2   How many pupils have SEND?

➢ In Kensington and Chelsea 12% of pupils have a have a statutory plan of SEN (statement or EHC plan) or are receiving SEN support. This compares to an average of 14.4% across England.[6]
➢ There are 544 pupils with a statement or EHC plan (2.1% of all pupils in Kensington and Chelsea)
➢ Kensington and Chelsea has a slightly lower percentage of secondary school children receiving SEN support or with an EHC plan than London and England

Figure 9: Percentage of state funded primary and secondary school age children, and percentage of school age children in all schools, who have an EHC plan or are receiving SEN support in Kensington and Chelsea, January 2017
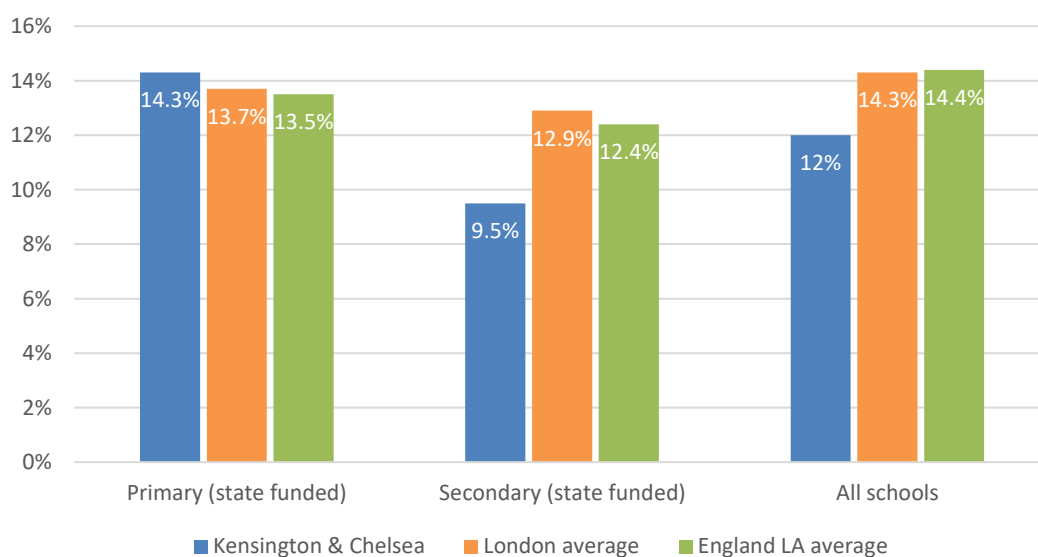
Source: DfE Special educational needs in England: table 14, January 2017

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[5] Gray, P (2017) External review of Westminster's spend on children and young people with high needs

[6] NB these figures, are for pupils attending schools in Kensington and Chelsea. They do not include children and young people for whom Kensington and Chelsea is responsible but has placed out of borough

4.2.3 Trends over time

➢ The percentages of pupils with a statement or EHC plan in Kensington and Chelsea has been about two thirds of the inner London average since 2010. (Inner London 3% and Kensington and Chelsea 2.1% in 2017)

➢ The number of pupils with SEN support increased since 2010

➢ The number of pupils with SEN support (without statements or plans) increased between 2016 and 2017.

➢ Trends show a slight decrease in numbers of pupils receiving SEN support following a report by Ofsted in 2010 which criticised schools for identifying too many children as having SEN.

Figure 10: Percentage of pupils with a statement / EHC plan 2010-2017
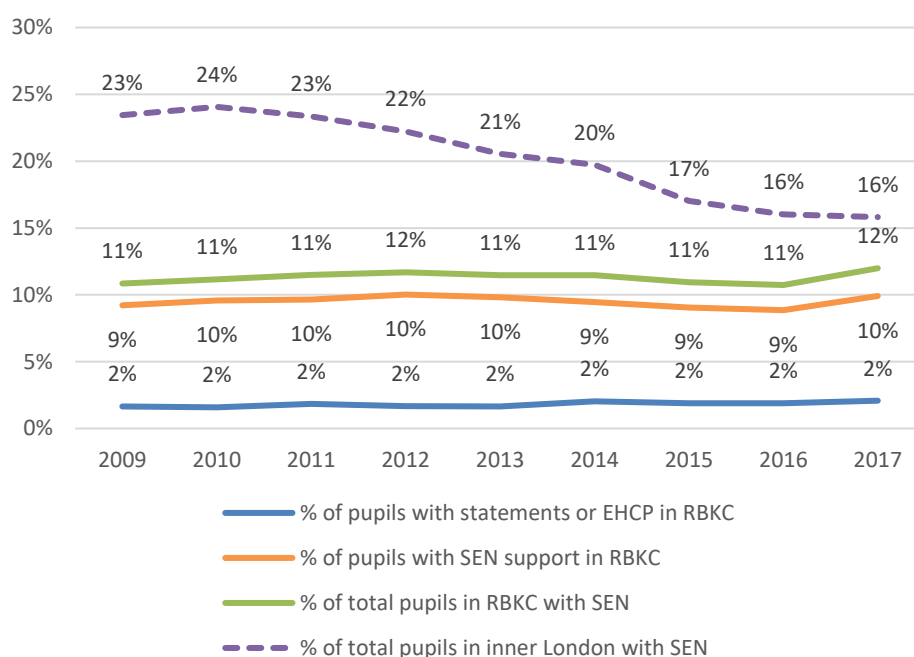
Source: DfE Special Educational Needs January 2017

4.2.4 Types of SEN needs locally

➢ The largest proportion of primary need amongst those with SEN is speech, language and communication needs in primary school (28%), however this is below the inner London average (38%)

➢ The largest proportion of primary need amongst those with SEN in secondary schools is social, emotional mental health needs. This is in line with the inner London average.

Figure 11: Percentage of state-funded primary and secondary school pupils with SEN, by primary need

Legend:
- RBKC: Primary
- RBKC: Secondary
- Inner London: Primary
- Inner London: Secondary
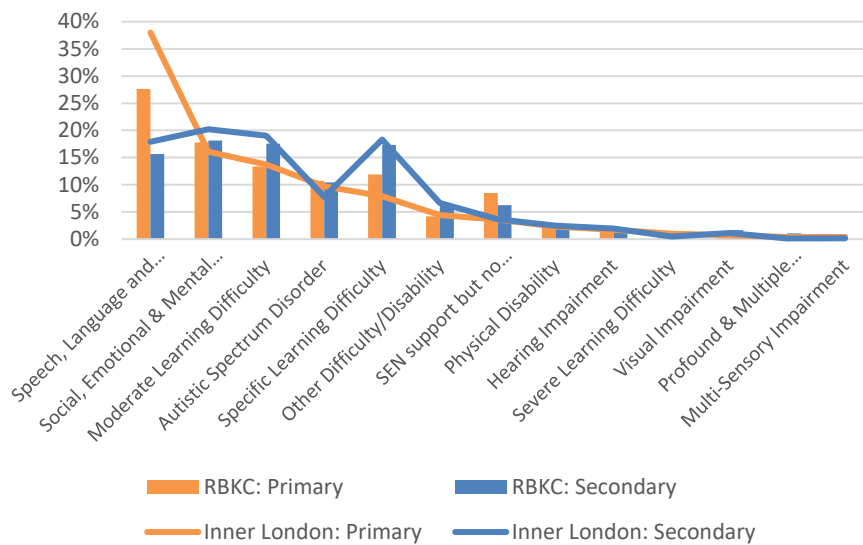
Kensington and Chelsea have a high percentage (32%) of special school pupils recorded as having 'other difficulty/disability' as their primary need. This possibly suggests a concern with accurate reporting.

Figure 12: Percentage of state-funded special school pupils with SEN, by primary need

Legend:
- Inner London
- Kensington and Chelsea
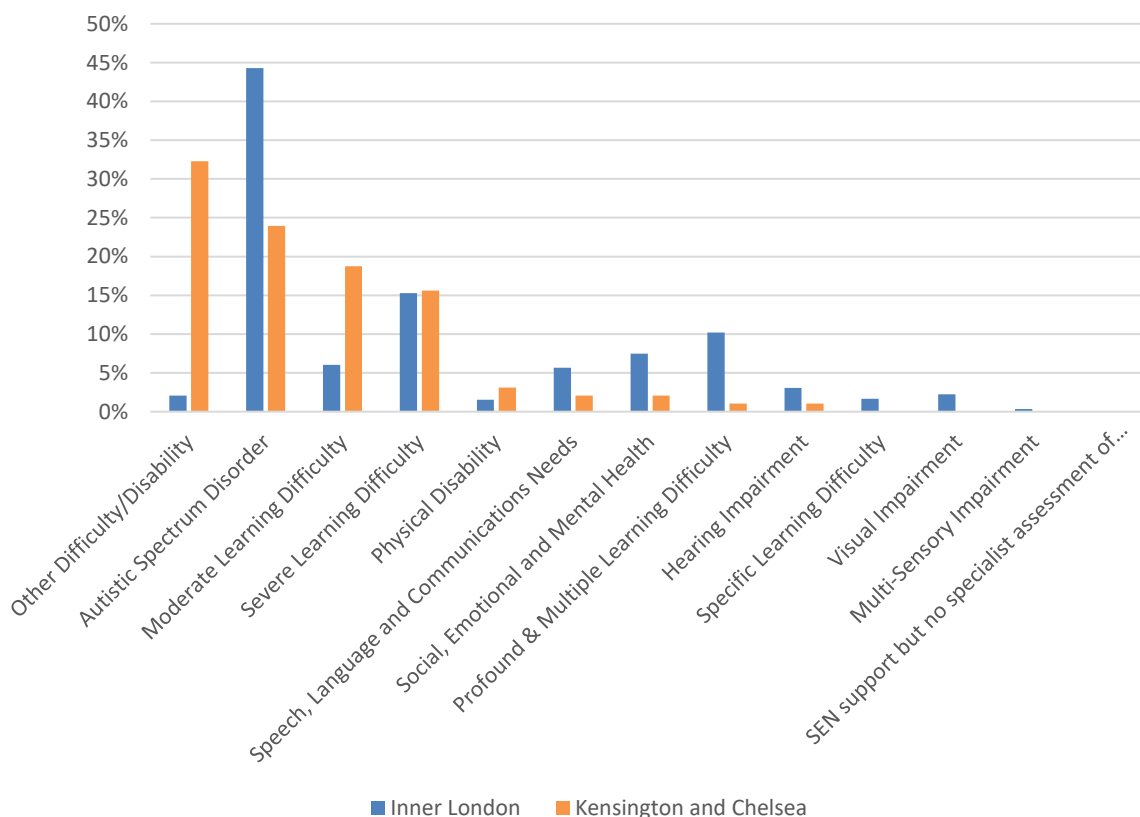
4.2.5 Impact on educational attainment – Key Stage 2 and 4

The SEN Code of Practice states that ambitious standards should also be expected for children with complex needs and disabilities. Nationally, fewer pupils with SEN support and a statement / EHC plan are achieving the expected standard for reading, writing and mathematics at key stage 2 compared to pupils with no identified SEN.

➤ A higher percentage of Kensington and Chelsea pupils with SEN are reaching the expected standard than compared with inner London and the national average

Figure 13: Percentage of pupils reaching the expected standard in reading, writing and mathematics at key stage 2 by SEN provision, 2017
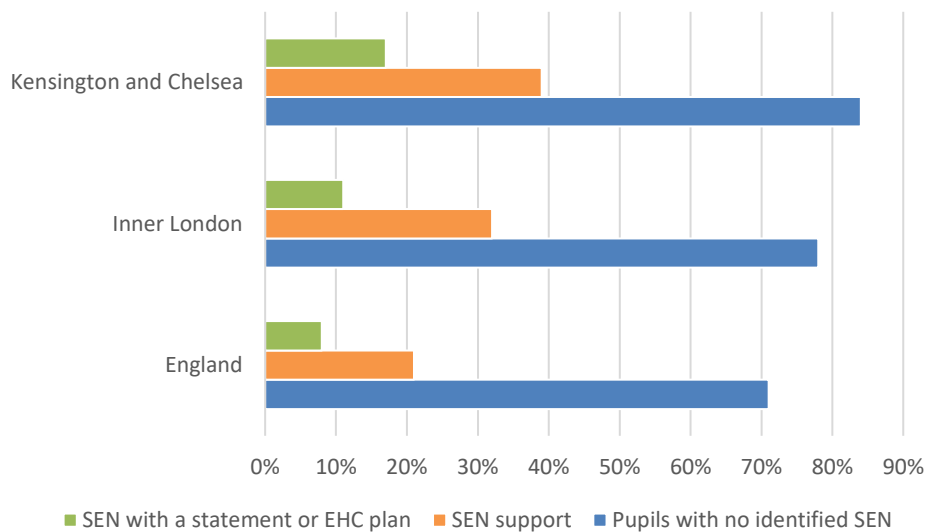
Source: DfE Key Stage 2 statistics, September 2018

> **Attainment 8** measures the achievement of a pupil at Key Stage 4 across 8 qualifications including mathematics and English (both of which are double weighted). Each individual grade a pupil achieves is assigned a point score, A* having the highest point score, which is then used to calculate a pupil's Attainment 8 score.

➤ Pupils with a plan or statement or receiving SEN support have a similar average attainment 8 score in Kensington and Chelsea as inner London

Figure 14: Average Attainment 8 score per pupil at KS4, 2016/17

Attainment 8 score (in points)

■ SEN with a statement or EHC plan ■ SEN support ■ Pupils with no identified SEN
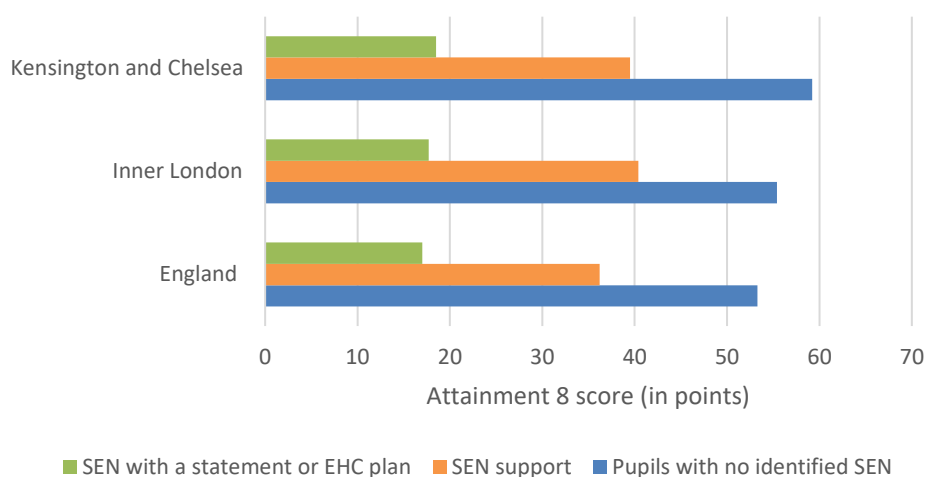
Source: DfE - GCSE and equivalent attainment by pupil characteristics, January 2018

➤ There is a higher percentage of persistent absentees amongst pupils with SEN in Kensington and Chelsea, across inner London and England than the average for all pupils.

➤ Children with any form of SEN are significantly more likely to have at least one fixed term exclusion[7]

4.3 Transition years and outcomes post 16

Children with SEND do less well on a range of outcomes that affect their long term future; academic performance is lower, exclusion and absence rates are higher, higher numbers go on to be not in education, employment or training (NEET) or in youth custody. Nationally, prison populations have a high prevalence of people with learning difficulties; in 2012, 18% of young offenders had a statement of SEN compared with 3% of the general population (Jacobson, Bhardwa, Gyateng, Hunter, & Hough, 2010).

Although numbers have decreased, the highest numbers nationally for Statements / EHC Plans is in pupils aged 11-15. As there have only been EHC plans available for 20-25 year olds since 2015, numbers are low but expected to rise.

Participation in education or training is important for young people's outcomes, but Ofsted have reported insufficient transition arrangements for people with SEND (Ofsted, 2011) (Ofsted, 2016). The Children and Families Act 2014 put new duties on the further education sector to support young people with SEND (with or without an EHC Plan / Statement) in further education up to age 25. Guidance for institutions such as further education colleges, sixth-form colleges, 16-19 academies and special post-16 institutions has been produced by the Department for Education (Education, Department for, 2015).

Employment and further education rates for people with SEND are below the average for their age group.

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[7] **DfE statistics SEN absences and exclusions** (accessed 28 June 2018)

4.3.1 What do we know locally?

➢ As of June 2017, Kensington and Chelsea had the same percentage of participation in education or training amongst the SEND as the national average (87%) but 5% less than the inner London average (92%)

Figure 15: Proportion of 16-17 year olds recorded in education and training by SEND, June 2017

- 16/17 yr olds without SEND in education or training
- 16/17 yr olds with SEND in education or training
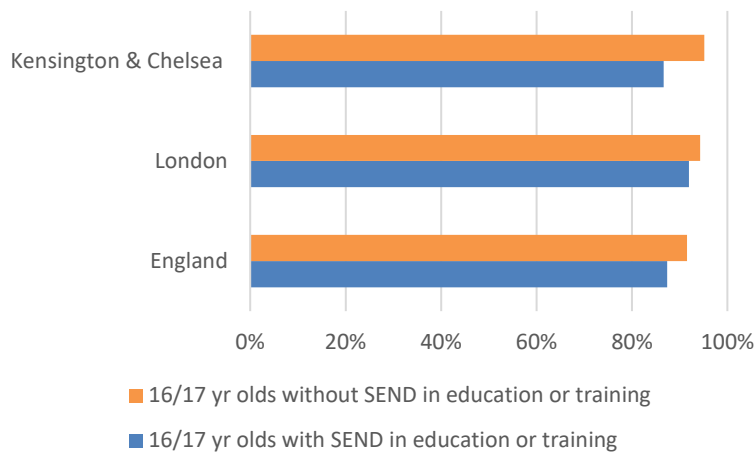
Source: DfE Participation in Education and Training figures, 2017

The West London Alliance of west London boroughs works with employers and education providers in West London to facilitate and support the establishment and development of supported internships and supported employment initiatives.

5 Pathway to support

5.1 Special educational needs support and Education, Health and Care Plans

If a child has special educational needs, they will be able to access help, called SEN support from an early years setting such as a nursery school, their school, and further education institutions such as colleges and 16-19 academies. Children and young people with more complex needs might instead need an Education, Health and Care Plan.

5.1.1 SEN Support

Getting SEN support happens in four stages[8]:
1. **Assess:** Discussions between teachers, special educational needs coordinator (SENCO) and parents and carers
2. **Plan:** All have a say in the support the child will receive
3. **Do:** The child's nursery or school will put the plan in place.
4. **Review:** Review the child's progress

[Pathway to SEN support flowchart](#)

The SEN Support Cohort Action Plan has identified five areas for improvement. One area is to support schools in revising their SEN information report where children, young people and parents / carers are at the heart of the co-production. This includes co-producing a SEN support fact sheet explaining how the 'graduated approach' works in schools, including information around transition.

A SEN Cohort Workstream was set up in 2017 to deliver these areas of improvement, including parents, SENCOs, Head Teachers, Educational Psychologists, health professionals, commissioners and social care professionals. The group plan to build up a shared understanding across the across the local area of this group of children, how their needs are currently being met and clarity on the respective roles and responsibilities of all partners in identifying and providing additional support.

Amongst the many results achieved thus far, SENCOs have reported they are more confident in providing children with SEN Support, the number of hits to the Local Offer website has increased and there is greater collaboration and sharing good practice between mainstream and special schools.

5.1.2 Education Health and Care Plan Assessment

An EHC plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs, and set out the specific, additional support to meet those needs.[9] Parents, doctors, health visitors, teachers, family friends and young person aged 16-25 can request an assessment for an EHC plan. If the Education Health and Care Needs Assessment shows that the special educational needs provision

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[8] NHS Choices. *Learning disabilities.*
https://www.nhs.uk/livewell/childrenwithalearningdisability/pages/education.aspx (accessed 28 June 2018)
[9] NHS Choices: Special Educational Needs NHS Choices. *Learning disabilities.*
https://www.nhs.uk/livewell/childrenwithalearningdisability/pages/education.aspx (accessed 28 June 2018)

required is over and above what is available in the Local Offer, then the Local Authority will issue an EHC Plan.

EHC Plan assessments

In Kensington and Chelsea the Special Educational Needs (SEN) Service co-ordinate statutory assessment processes for young people with special educational needs and/or disability 0-25 years. This service provides SEN Key Workers, who coordinate the multi-agency approach and act as the single point of contact for parents and/or young people during the EHC assessment process.

Regulations set out that the overall time it takes from the local authority receiving a request for an assessment and the final EHC plan being issued (if one is required) should be no longer than 20 weeks. In 2016, only 33% of assessments in Kensington and Chelsea were conducted within the statutory time of 20 weeks, however, this has risen to 51% in 2017.

Figure 16: Percentage of new EHC plans issued within 20 weeks in Kensington and Chelsea
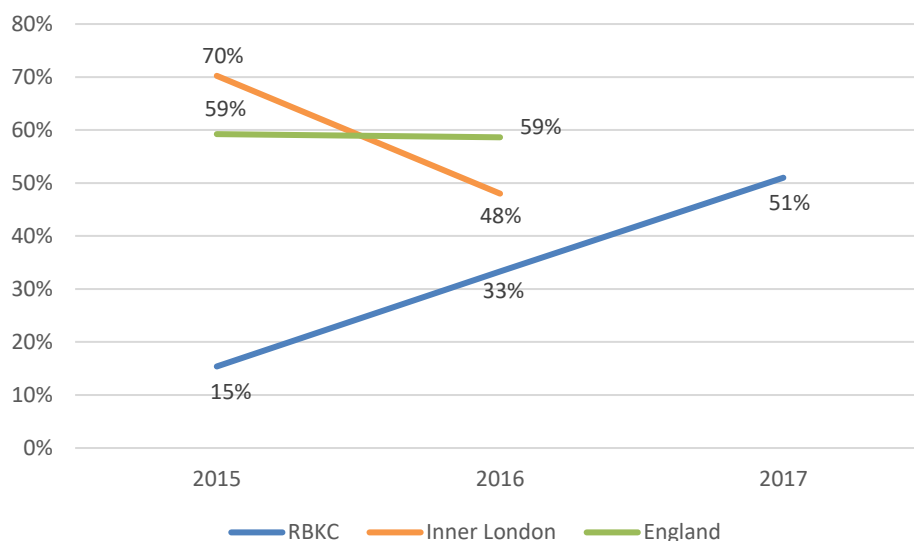
 Source: Statements of SEN and EHC plans, 2017, table 8, excluding exceptions

Conducting an Education, Health and Care Needs Assessment flowchart

5.1.3   Placement of children and young people with a statement or EHC Plan

The local authority has to discuss the placement with the proposed school to ensure that it is suitable before naming it in the EHCP. The majority of children and young people with a statement or EHC plan in Kensington and Chelsea are educated in a mainstream school, a special school or an academy.

Figure 17: Placement of children and young people with a statement or EHC plan in Kensington and Chelsea
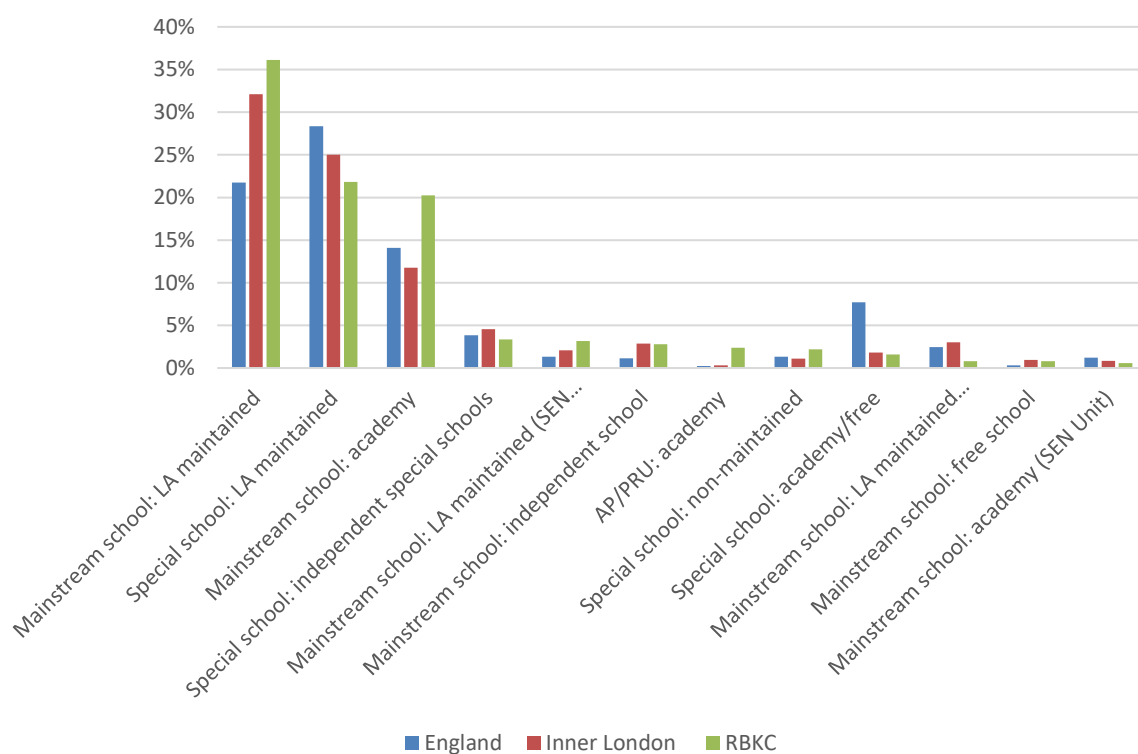
Source: Special educational needs and disability (SEND) and high needs (January 2017)

5.2 Diagnosing complex needs

Where needs are more complex, health professionals including the Child Development Service in the local NHS trusts may undertake the assessment and diagnosis.

The Child Development Service is provided by Imperial College Healthcare NHS Trust in the north of Kensington and Chelsea, and by Chelsea and Westminster NHS Trust in the south.

A Child Development Services offers comprehensive multidisciplinary and multi-agency services for children with neurodisabilities, communication disorders, and behavioural problems, as well as providing medical input into EHC Plans. The service assesses and treats children with developmental delay neurodisabilities, social communication disorders, autism and ADHD. Many children and young people within this group have complex medical conditions. In addition to their primary neurological condition, many have a variety of secondary associated problems requiring medical management, e.g. gastro-oesophageal reflux, seizures, constipation.

5.3 Referrals to the Imperial College NHS Trust Child Development Service

As of November 2017, referrals to the service have increased significantly (47%) since 2012/13. In particular, the Autism pathway has increased by 80% and the general pathway has increased by 31%. Both neurodisability and ADHD have remained static, with around 60-70 cases a year for the former,

and around 30 cases a year for the latter. Referrals are from all areas the Child Development Service covers including north of Kensington and Chelsea and north and centre of Westminster.

Figure 18: New patients referred to the service

➢ General developmental delay has been the largest reason for referral (from the north of Kensington and Chelsea and centre and north of Westminster) in the first three quarters of 2016/17 and 2017/18 and predicted to be in the fourth quarter of 2017/18, followed closely by social communication disorder.

Figure 19: Percentage of all referrals to the Child Development Service by pathway

5.4 Waiting times at Imperial College NHS Trust Child Development Service

NICE guidelines state that an autism diagnostic assessment should start within three months of the referral to the autism team (NICE, 2011 (updated 2017)). Average waiting times for referral to diagnosis of ASD for 4.5 year olds and under was 41 weeks as at November 2017.

Figure 20: Number of weeks waiting time for new referrals at Imperial College NHS Trust CDS
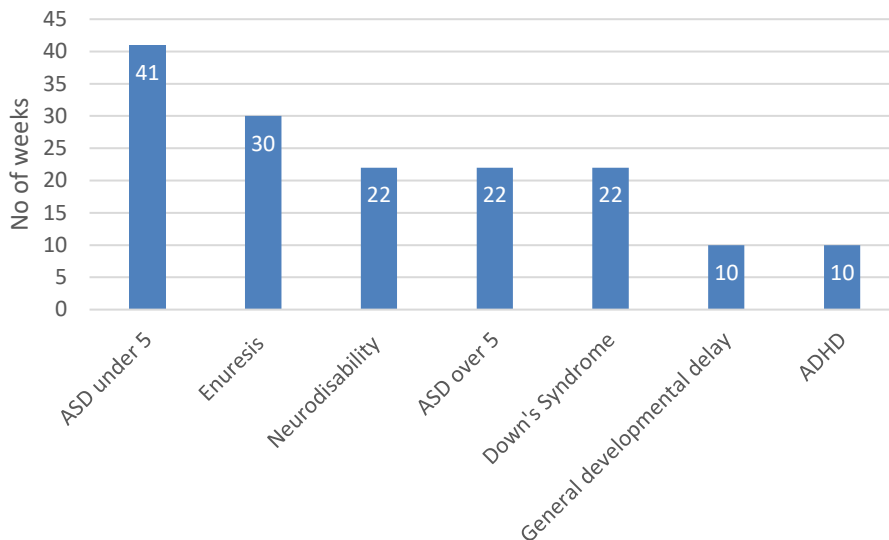
Source: CLCH Imperial NHS Trust Child Development Service, November 2017

5.5 Referrals to the Chelsea and Westminster Hospital NHS Trust Child Development Service

➢ There were 164 referrals to the Child Development Service from Kensington and Chelsea in 2017/18
➢ Most referrals in the south of Kensington and Chelsea require appointments with a multi-disciplinary team, the most resource intensive type of appointment.

Figure 21: Referrals to the Cheyne Child Development Service by appointment type
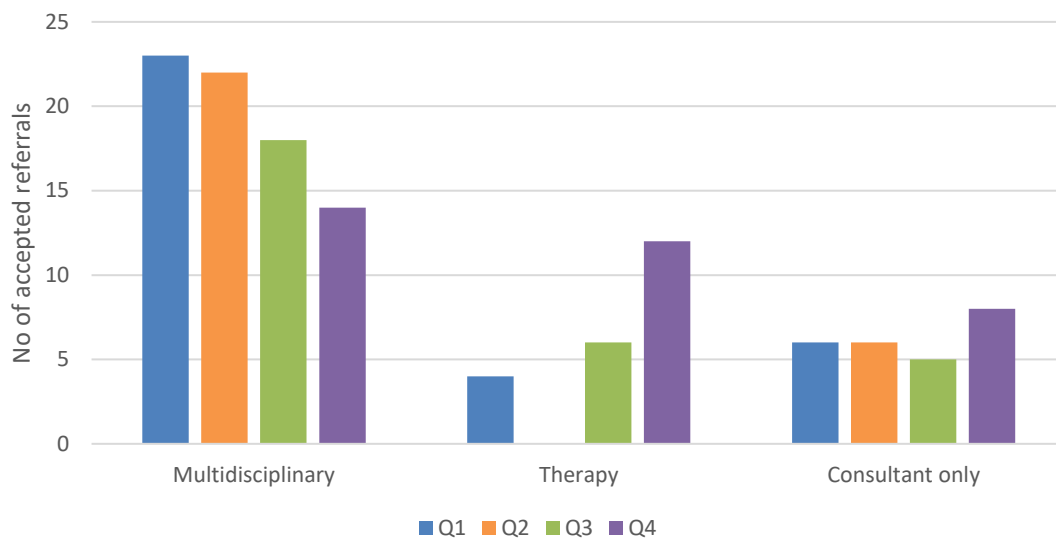
Source: Chelsea and Westminster Hospital NHS Trust, Cheyne Child Development Service Q1-2, 2016/17 and 2017/18

5.6   Waiting time in the south of Kensington and Chelsea

➢ Average waiting times for referral to diagnosis of ASD for 4.5 year olds and older was, on average, longer than a year in 2017/18.

➢ *NB. This is the average waiting for the service, which includes referrals from parts of Westminster, Kensington and Chelsea and Hammersmith & Fulham*

Figure 22: Waiting times for completed assessment for *under* 4.5 year olds
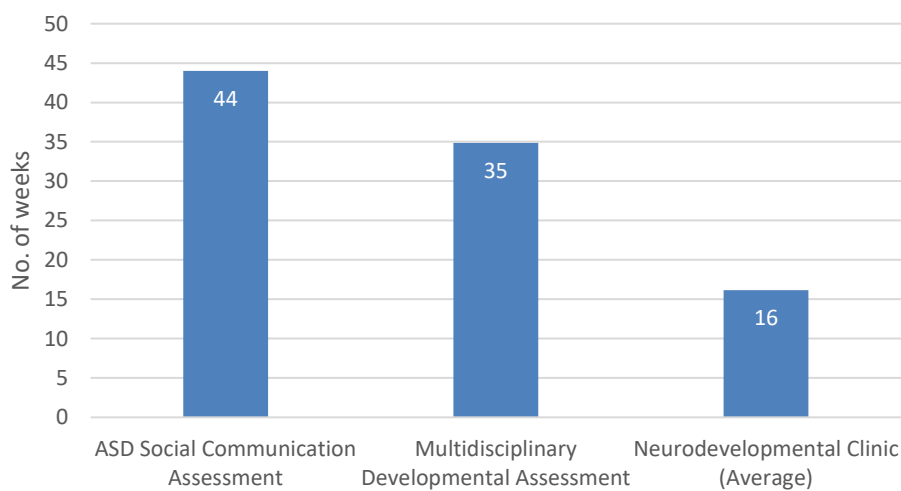
Source: Chelsea and Westminster NHS Trust Child Development Service, 2017/18

Figure 23: Waiting times for completed assessment for *over* 4.5 year olds

In 2017 the government committed to collecting and publishing autism diagnosis waiting times in England, which would enable comparison to other inner London boroughs and the national average.

➢ The service has seen an exponential increase in demand compared to little increase in capacity in the last ten years. A waiting time of over one year incurs fines for the service.

➢ *NB. Referrals here reflect referrals from areas in Westminster, Kensington and Chelsea and Hammersmith & Fulham that the service covers, so are higher numbers than the individual boroughs referrals above*

Figure 24: Number of referrals per year

6 Types of special educational needs and disabilities in detail

The most common special educational need nationally and locally is 'speech, language and communication needs', followed by 'social, emotional and mental health'. Although the numbers of Autistic Spectrum Disorder and moderate, severe and profound and multiple learning disabilities are low, their needs are high and so will be explored in more detail.

7 Speech, language and communication needs

7.1 Background

SLCN charity and educator I CAN categorises SLCN as 'persistent' (long-term) – or 'transient', meaning that children can usually be supported to catch up with their peers (I CAN, 2006).

> 'Children with speech, language and communication needs (SLCN) find it difficult to communicate with others. Some children find it hard to: understand what is said to them, form words and construct sentences, find the right words to express thoughts and feelings, and understand rules for social interaction and conversation.' – I CAN

7.2 What do we know nationally?

School-age children with SLCN perceive their quality of life as worse than their peers. They struggle with social acceptance, being bullied and managing moods and emotions. They are more likely than their peers to develop social, emotional or mental health difficulties (Lindsay & Dockrell, 2012).

Language skills are linked to academic success and positive self-esteem (I CAN, 2006). Young people with language difficulties are less likely to remain in post 16 education and are more likely to go on to manual or partly skilled jobs, have more breaks in employment, more interpersonal problems at work, and more instances of redundancy. Employment and education have a significant impact on health outcomes (Public Health England & the UCL Institute of Health Equity, 2014).

Poor conversational skills lead to problems in communication and forming friendships. Both adults and children with SLCN have a higher risk of social isolation. Children report a higher risk of bullying. Without support, children with SLCN are more likely to develop behavioural difficulties and mental health problems.

Home Office research has found that 35% of offenders have speaking and listening skills at a basic level (Public Health England, 2016).

➢ Nationally, there are 234,076 pupils (20% of all pupils with SEN) in state funded schools receiving speech, language and communications support

➢ Nationally, it is known of all children aged 4 and under receiving SEN support, 56% have a primary need of SLCN.

Prevalence by demography

➤ **Gender:** Nationally, the female-to-male ratio of pupils receiving SEN support for SLCN is 1:2.3

➤ **ESOL:** Nationally, 26.2% of pupils receiving SEN support for SLCN, and 18.1% of those with a statement/EHCP, have a first language other than English.

➤ **Ethnicity:** Nationally, there is a slightly disproportionate prevalence in BME children, who account for 38% of all those receiving SEN support for SCLN.

7.3   What do we know locally?

➤ There were 392 early years' referrals to the SLT team in 2017/18 (including Q4 predictions). Please see Early Years section above for more information.

➤ In Kensington and Chelsea, there are 380 pupils receiving speech, language and communications support (12% of all pupils with SEN) and it is the most common reason for SEN support among primary school pupils

➤ Kensington and Chelsea follows the trend as seen in inner London and England, with a smaller percentage of those receiving SEN support receiving SLCN support in secondary school.

➤ This suggests SLCN support at primary school can bring those children with additional needs to the same level as their peers without support by the time they reach secondary school, demonstrating the importance of speech and language support in early years and primary years.

Figure 25: Numbers of pupils with SLCN and percentages of pupils with SEN that have SLCN as their primary need

Legend:
- No of pupils with SLCN in RBKC
- % of support recipients whose primary need is SLCN in RBKC
- % of support recipients whose primary need is SLCN in inner London
- % of support recipients whose primary need is SLCN in England
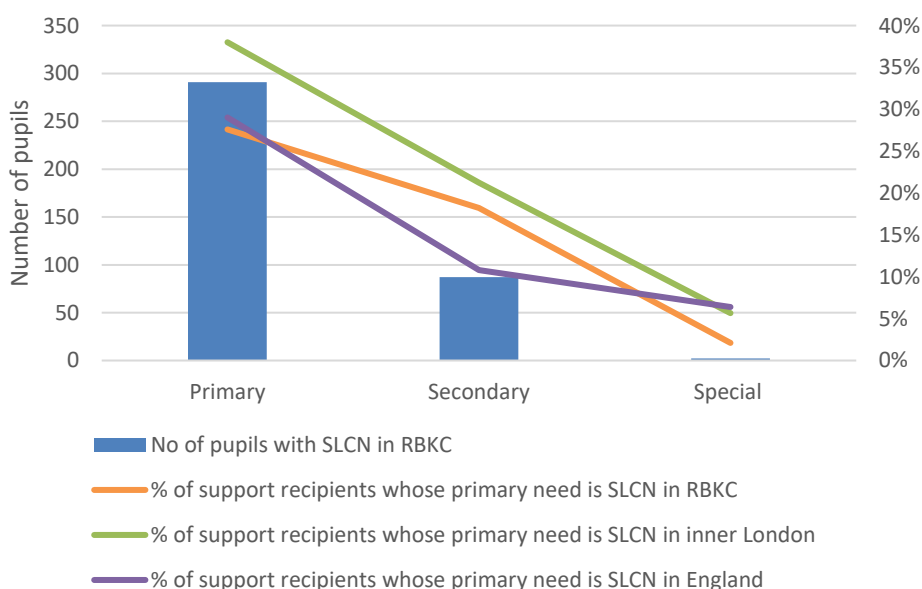
Source: DfE Special educational needs, state funded schools, number of pupils with SEN by primary type of need: SLCN

➤ Kensington and Chelsea has a lower percentage of children with SLCN, than inner London

Figure 26: Percentage of all pupils with SLCN as their primary need

True prevalence may be much higher. The Department of Health's guidance to Health & Wellbeing Boards (Department of Health, 2014) suggests that as many as 10% of children may have some form of SLCN. This suggests that there are possibly children who need support that are not receiving it.

Within secondary schools nationally, I CAN describes a 'vicious cycle of support' of low awareness, few support resources, and poor identification of need. This then 'justifies' restricted service, and so understanding remains limited (I CAN, 2011).

7.3.1   Future Trends

The GLA pupil roll projections suggest that numbers of primary school children with SEN will decrease between 2017 and 2023. This is likely responsible for the projected -6% decrease in children with SLCN.

Based on 2013-2017 trends, it is predicted that there will be a steady number of pupils with SLCN that go to school *and* live in Kensington and Chelsea between 2017 and 2023. *This figure excludes pupils who attend school in Kensington and Chelsea but live in another borough.*

Figure 27: Number and projected number of pupils that go to school *and* live in Kensington and Chelsea with SLCN
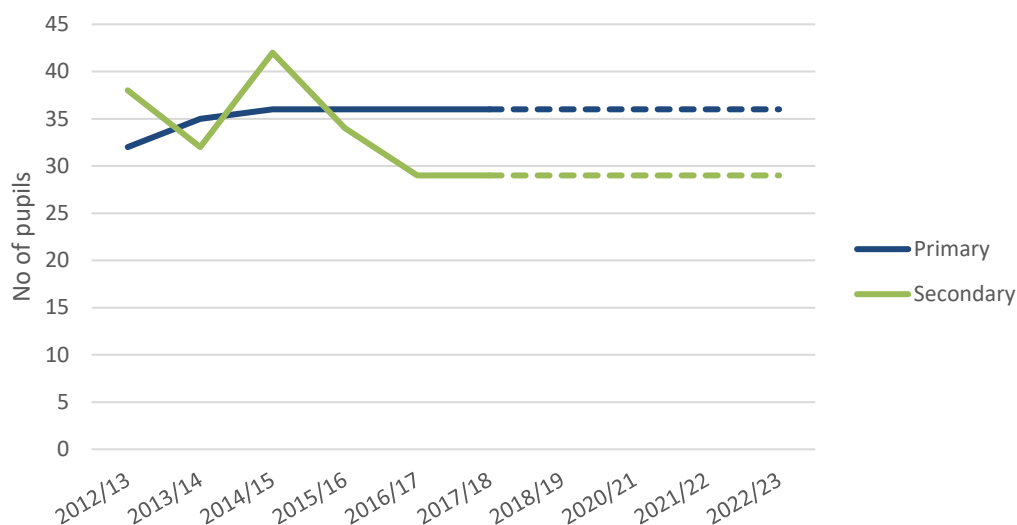
The Joint Commissioning plan 2018/19 has identified speech, language and communication needs as a priority:

The challenge	Proposed actions
A service review into speech, language and communication need found there is a reliance on specialist intervention and a need to strengthen early intervention. Following that, the LA and CCG have been working closely with the provider to develop and pilot a reshaped service, whilst working towards developing a more graduated offer. During this period, the commissioning team have started to work proactively with schools, early years' and further education settings to understand their role in meeting need and how the local offer can be used to compliment the services provided by the SaLT service.	1. New service model implemented by CLCH, which manages demand and is more cost effective 2. 0-25 graduated model in place by October 2019 3. Develop new whole-system approach to speech, language and communication, offering increased support for early intervention and for children and young people below the EHC Plan threshold.

7.4   What works?

In response to the Children & Families Act, the Royal College of Speech & Language Therapists published guidance for speech and language therapists (SLTs) on how to meet the Act's requirements (Howe, et al., 2016). This includes making contributions to EHCPs and deciding on outcomes and targets for children and young people.

I CAN identifies the following good practice strategies (I CAN, 2008) to create a 'communication supportive' environment for primary school pupils with SLCN:
- An audit of the environment
- Knowledge of language development, language levels of the children and the language demands in the environment
- Adapting adult language so it is not a barrier to learning or communication
- Facilitating opportunities for children to interact and use language in different situations, with different people at an appropriate level
- Creating an ethos where it is acceptable not to know and teaching children how to monitor their own understanding.
- Raising children's awareness of their strengths and needs.
- Ensuring children can participate and be involved in decision making concerning them
- Careful planning and information sharing between staff at times of transition.

In 2011, the Government's Communication Champion for children and young people, responsible for promoting the importance of good language skills, published a two-year follow-up (Gross, 2011) to the 2008 Bercow Report, which identified the following key success factors:
- Integrated health and education promotion and prevention with under 5s in disadvantaged areas
- Integrated, jointly commissioned care pathways for children with SLCN
- Approaches which build capacity in the children's workforce - sustained professional development that changes adults' interactions with children and helps them provide communication-supportive environments
- Approaches for children, young people and adults which build on their strengths rather than focusing on their weaknesses.

Characteristics of high-quality and cost-effective practice further included:
- Strategies for early identification and effective intervention for lower-level needs
- Schools and settings developing their own language leads
- A skill mix in the services provided, combining well-trained and supported learning support or therapy assistants and therapists/advisory teachers
- Specialist clinical experts employed to provide cost effective interventions – for example, stammering services in Leeds, Bristol and Tower Hamlets, where highly skilled early intervention eliminates stammering in over nine out of ten cases
- Speech and language therapy services provided in settings that minimise the rate of missed appointments (e.g. school or setting-based services)
- Services across the NHS and local authority working together to devise ways of reaching disadvantaged and 'harder-to-reach' children and families, in order to reduce inequalities and narrow gaps (for example, through supermarkets and parent/toddler drop-in clubs)

- SLCN services targeted at children and young people with behaviour difficulties
- Strategies to ensure that school staff play their part in supporting or delivering programmes devised by speech and language therapists
- Information and communication technology used to increase the reach of specialist services
- Commissioning of services on the basis of measurable outcomes for children
- Parents/carers of children with SLCN and young people themselves involved in service review and redesign
- Active partnerships sought with voluntary organisations

The Communication Champion report 'Better Communication: Shaping speech, language and communication services for children and young people' (Gascoigne, 2012) also describes numerous examples of innovative practice in service modelling and commissioning from across the country.

Case Study: Hartlepool

In Hartlepool, where there was very limited take-up of 2 year child development checks, children's services introduced '2 year birthday parties' in children's centres in the south of the city as part of the 0-3 programme.

All children who turned 2 in a given month were invited to a party with their families. There were many play opportunities, of which some element concentrated on community-led local development. These included nursery rhymes and early reading recognition. There was also a focus on activities that challenged families (e.g. use of dummies, toilet training) with an overall aim to nurture and upskill parents. The parties give professionals opportunities for positive role modelling and for providing information about a range of local services.

This approach was successful in engaging previously difficult to reach families. 50% of children attending had not previously accessed the development check before they came to the party. While at the party, all families received information about home learning opportunities and next stage development in speech, language and communication. The original pilot was held in one children's centre locality but has now been adopted across the town as good practice.

Professionals view

A workshop with local professionals from Children's Services and health (see appendix 1) identified inequities across the borough in SLCN provision; there are disparities from school to school regarding how much support is bought in. Transition between nursery and reception was also raised as an issue. They also noted uncertainty among service users about access to SLT and a perception of diminishing services.

Case Study: MEND: Mind, exercise, nutrition… Do it!

Mind, Exercise, Nutrition...Do it! (MEND) is an obesity prevention and treatment programme for children and young people. Mytime Active has been delivering the Teens programme at St. Marylebone Bridge CE School, a specialist speech and language school.

Working with year 9 and year 11 pupils for 1.5 hours a week, each sessions delivers the key health messages in an interactive and practical way that is tailored to the needs of the group. The ability of the students changes from class to class, year to year. The delivery team get to know the pupils and are able to assess their ability and in turn adapt the sessions accordingly. As a result MEND have seen each group develop in terms of their practical skills, confidence and ability. Activities include physical activity, nutrition and practical cooking skills.

The theory based sessions allow for the participants to make valuable contributions through active participation and peer learning in discussions - this encourages interaction and the sharing of ideas between participants along with physically completing a theory based activity, as opposed to them just sitting, listening and being told what to do. The essence of this section is to generate as many answers as possible from the participants and be accepting of what they have to offer. This in turn gives a sense of ownership and empowerment.

Each group gets to take part in a supermarket tour where they put their label reading skills to the test, reviewing the amount of fat, sugar and salt in popular food items. This is always a highlight and a great opportunity for the group to continue their learning outside of the classroom. For many of the young people, the cooking sessions are the first time they have tried certain foods and they always enjoy sitting down as a group to enjoy the dishes they have prepared.

Staff and students:

"The programme was very beneficial to the students, they really enjoyed learning about the sugar content in drinks, the interactive practical cooking sessions were fun as were the supermarket tours".

"It was really fun! Overall I really enjoyed it and everyone involved was really friendly and engaged well with the students.

"The cooking sessions were the best part"

MEND are currently running their fourth programme running up until March 2018.

8 Social, Emotional and Mental Health (SEMH)

8.1 Background

The Children and Families Act changed the terminology from 'Behavioural, Emotional and Social Difficulties' to 'social, emotional and mental health difficulties' to reflect the needs which may be affecting behaviour, rather than focusing on the behaviour.

The area includes social and emotional functioning, wellbeing, the ability to regulate self and behaviour and mental health difficulties. Children and young people who experience these difficulties may have a medical mental health diagnosis and may have special educational needs[10].

The SEND Code of Practice (Department for Education and Department of Health, 2015) states that schools and colleges should have clear processes to support children, including the management of any disruptive behaviour so it does not adversely affect other pupils.

8.2 What do we know nationally?

Social, emotional and mental health is important in childhood and adolescence as research tells us that this is when mental health issues commonly develop.

- ➢ 75% of lifetime mental health problems are established by the age of 17

- ➢ Around 10% of children and young people aged 5-16 have a diagnosed mental health condition (Department for Education, 2016)

- ➢ A further estimated 15% have less severe problems that put them at increased risk of developing mental health problems in the future

- ➢ Many children and young people with SEMH will also have other needs such as speech, language and communication needs (SLCN).

- ➢ Inequalities exist in mental health with a higher prevalence in children living within disrupted families, with parents who have no educational qualifications, in families living in poverty and in deprived areas. Looked after children are more likely to have a mental health condition. There is also variation by ethnicity with white, Pakistani or Bangladeshi 5-10 year olds more likely to have a mental disorder than black children (NICE, 2008)

8.3 What do we know locally?

- ➢ Social, emotional and mental health difficulties is the second most common reason a pupil with SEND might be receiving support in Kensington and Chelsea.

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[10] Royal College of Speech and Language Therapists. Social Emotional and Mental Health - Children and Young People: Overview (accessed 11 June 2018)

Figure 28: Numbers of pupils with SEMH and percentages of support recipients whose primary need is SEMH
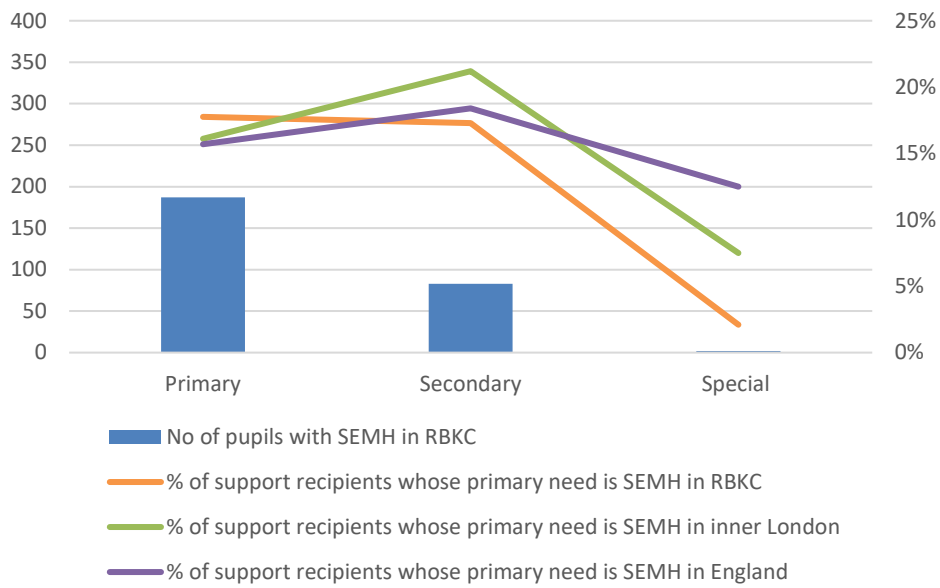
Legend:
- No of pupils with SEMH in RBKC
- % of support recipients whose primary need is SEMH in RBKC
- % of support recipients whose primary need is SEMH in inner London
- % of support recipients whose primary need is SEMH in England

Source: DfE Special educational needs, state funded primary, secondary and special schools, number of pupils with SEN by primary type of need: SEMH

➢ Kensington and Chelsea has under half the percentage of pupils receiving support for social, emotional and mental health in comparison to inner London and England, despite being one of the most common reasons for receiving support

Figure 29: Percentage of all pupils with social, emotional mental health
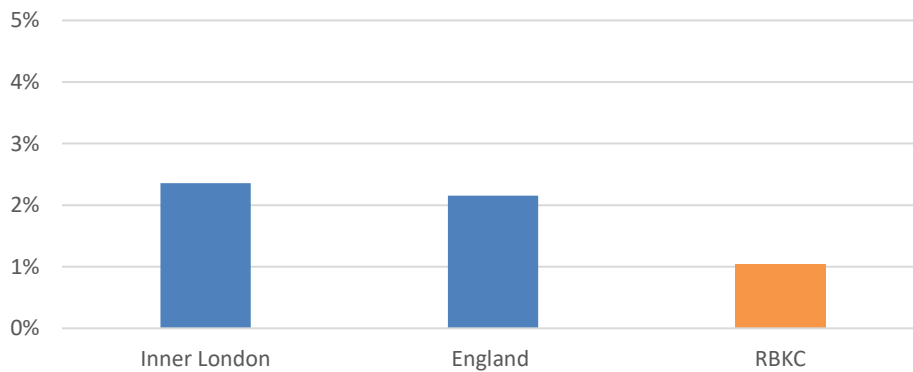
Source: DfE Special educational needs, state funded primary, secondary and special schools, number of pupils with SEN by primary type of need: SEMH

8.4   What works?

The following evidence based service model was developed by the National Children's Bureau to promote social and emotional wellbeing in schools and address mental health problems. The framework adopts a whole school, multi-component approach, which is in line with other guidance and research. There is clear evidence from well-conducted systematic reviews to support schools in employing the following approaches to improve outcomes:

ENGAGE THE WHOLE COMMUNITY

- Engage pupils through encouraging pupil voice, authentic involvement in learning, decision-making, and peer-led approaches
- Engage parents/carers and families in genuine participation, particularly those of pupils in difficulties whose families may feel blamed and stigmatised

Adopt whole-school thinking

- Use a 'whole school approach', which ensures that all parts of the school organisation work coherently together
- Provide a solid base of positive universal work to promote well-being and help prevent problems
- Develop a supportive school and classroom climate and ethos which builds a sense of connectedness, focus and purpose, the acceptance of emotion, respect, warm, relationships and communication and the celebration of difference
- Start early with skills based programmes, preventive work, the identification of difficulties and targeted interventions. Work intensively, coherently, and carry on for the long term
- Promote staff well-being, and particularly address staff stress levels

Prioritise professional learning and staff development

- Understand the risk factors to well-being, and help pupils develop the resilience to overcome adverse circumstances
- Raise staff awareness about mental health problems and the school's role in intervening early
- Base their response on a sound understanding of child and adolescent development
- Help all pupils cope with predictable changes and transitions, and keep abreast of new challenges posed by technology.

Develop supportive policy

- Ensure that there are robust policies and practice in areas such as behaviour, anti-bullying and diversity, including tackling prejudice and stigma around mental health

Implement targeted programmes and interventions (including curriculum)

- Ensure high-quality implementation of specific programmes and interventions
- Explicitly teach social and emotional skills, attitudes and values, using well-trained and enthusiastic teachers and positive, experiential and interactive methods. Integrate this learning into the mainstream processes of school life

Implement targeted responses and identify specialist pathways

- Provide more intense work on social and emotional skill development for pupils in difficulties, including one-to-one and group work
- Use specialist staff to initiate innovative and specialist programmes to ensure they are implemented authentically, then transfer responsibility to mainstream staff whenever possible, to ensure sustainability and integration
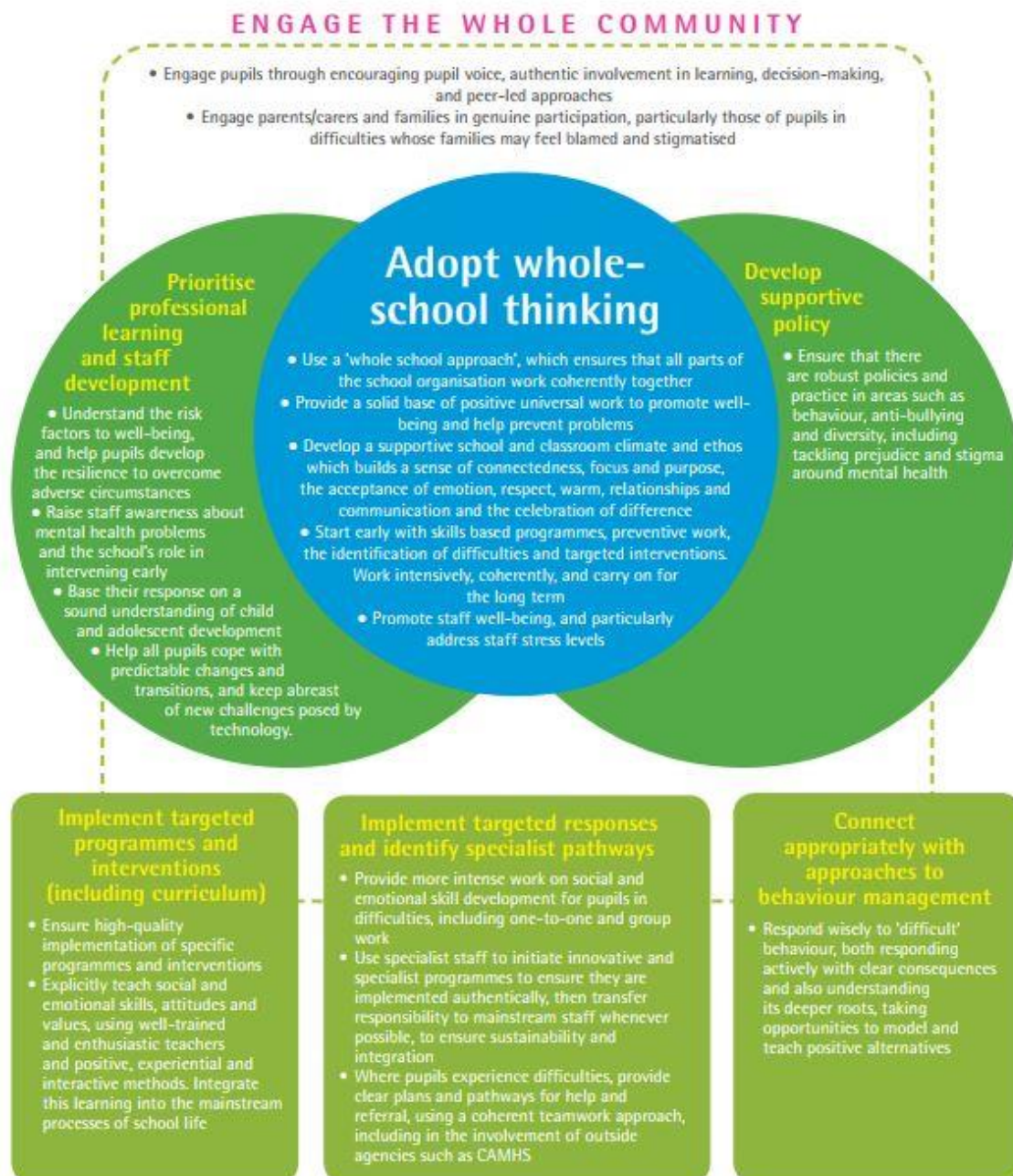- Where pupils experience difficulties, provide clear plans and pathways for help and referral, using a coherent teamwork approach, including in the involvement of outside agencies such as CAMHS

Connect appropriately with approaches to behaviour management

- Respond wisely to 'difficult' behaviour, both responding actively with clear consequences and also understanding its deeper roots, taking opportunities to model and teach positive alternatives

Source: National Children's Bureau: Framework for promoting well-being and responding to mental health in schools

NICE have published a Local Government Briefing (NICE, 2013) which summarises key points from their guidance on the social and emotional wellbeing of children and young people. For example, guidance is included for strategy and commissioning; children in primary and secondary education; and home visiting, early education and childcare.

Universal approaches to promoting social and emotional wellbeing in primary school include schools helping parents to develop parenting skills and a stepped approach to preventing mental health problems. Targeted approaches include training teachers and staff to identify the early signs of emotional distress, anxiety and behavioural difficulties in children.

The recent report *Mental health and behaviour in schools* (Department for Education, 2016) further summarises some of the evidence based interventions to promote resilience and address mental health and wellbeing in schools, including PSHE education; classroom management and small group work; counselling; access to child psychologist; developing social skills; working with parents; and peer mentoring.

Case study: Emma's story

Emma is a 10-year-old looked after child with social, emotional and mental health needs. She had extreme social difficulties, including being highly aggressive both physically and verbally.

She had very poor social communication skills, very poor ability to recognise and respond to the communications of others, emotional literacy difficulties and extreme difficulties managing her emotions.

She could not make or keep friends and she had regular exclusions from school. Parents of other children complained about her behaviour and school staff labelled her as 'the devil'.

Aged seven, she was about to move carers, geographical area, and to another mainstream school.

Given concerns about her ability to continue in mainstream education, she was referred to speech and language therapy services by her social worker.

Following work with the SLT, Emma's social communication and interaction skills with other children greatly improved, as did her ability to build new relationships as well as maintain the ones she had formed.

She got better at managing her emotions when things did not go as she would like, and also at recognising what information was appropriate to speak about, depending on her audience (i.e. recognising private versus public subject matters). She learned phrases to use to negotiate and compromise.

Her file has now been closed, very few difficulties have been reported since, and she has continued in mainstream education for three years.

Source: The Royal College of Speech and Language Therapists

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9   Specific Learning Difficulties

9.1   Background

Learning difficulties (called specific learning difficulties or SpLD in an educational context) are conditions which may affect learning and communication.   The most common learning difficulties are dyslexia, dyscalculia, dyspraxia, dysgraphia, and attention deficit hyperactivity disorder (ADHD).

9.2   What do we know nationally?

- Nationally, it is known that 2.2% of all children aged 4 and under receiving SEN support, have a primary need of SpLD. However, accurate local data is not available for this age group.
- Specific learning difficulties are the most common primary need for children aged 16+, accounting for 27.9% of those children (compared to 15.6% of all children receiving support).

Prevalence by demography

- **Gender:** The female-to-male ration of school-aged children receiving SEN support for SpLD 1:1.6. For children with a statement of SEN or EHCP, the ratio is 1:2.6. These are very slightly narrower than the average gender ratios for SEN support and statements/EHCPs: respectively 1:1.8 and 1:2.7.
- **Ethnicity:** BME children account for 18.3% of all those receiving SEN support for SpLD. This is an underrepresentation: this group makes up on 30% of school-age children generally.
- **ESOL:** 8.8% of pupils receiving SEN support for SpLD, and 8% of those with a statement/EHCP, have a first language other than English. This cohort makes up 14.3% of the general school population and 16.1/14/1% of the SEN/statement of EHCP population. This may indicate under-recognition of SpLD in children whose first language is not English.
- **Free School Meals:** All children with SEN are almost twice as likely to be claiming free school meals as the general school population (27.2% vs 14.3%). This is less true of pupils with SpLD: 18.7% are eligible.

Health and life outcomes

- In adolescents, dyslexia has been associated with anxiety and depression, aggression, sleep problems and delinquent behaviour (Eissa, 2010).
- Children and adults with literacy difficulties (e.g. dyslexia, dysgraphia) report feeling humiliated, ridiculed and bullied. Low educational achievement and early disengagement are well-understood risk factors for poor health outcomes in later life (Public Health England & the UCL Institute of Health Equity, 2014).
- ADHD is associated with higher rates of job termination and lower performance ratings, poorer family relationships; higher rates of physical injury (20.4% vs 11.5%). substance misuse and sexual risk, and a slightly higher suicide rate (Nigg J. , 2012)
- Children and adolescents with Dyspraxia/DCD tend to be more sedentary, more overweight, less fit, and at a higher risk of coronary vascular disease than their peers (Caçola, 2016).

9.3   What do we know locally?

- ➤ There are 200 school-aged children in Kensington and Chelsea receiving SEN support primarily for specific learning difficulties as of January 2017. (1.7% of primary pupils, 1.5% of secondary pupils and 0.8% of special school pupils)

Figure 30: Percentage of all pupils in each school with a specific learning difficulty
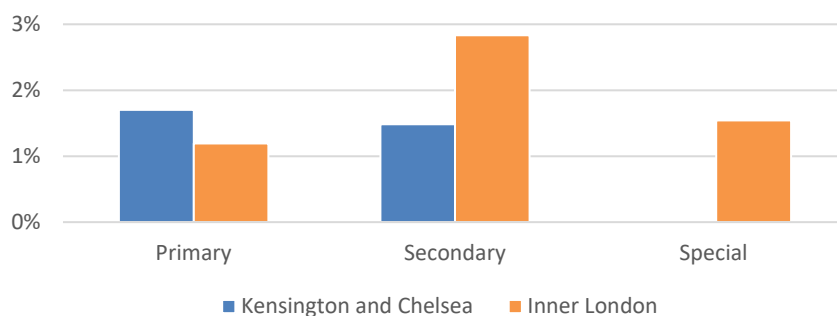
Sources: DfE Statistics: Special Educational Needs and School and pupil numbers, January 2017

9.4   What works?

A 2012 report (Dyslexia Action, 2012) identified the following aspects of best practice in assessment and follow up of SpLD;

- Better tracking and monitoring of children as they progress from pre-school through to adulthood.
- A clear policy on where the responsibility for tracking sits and better use and co-ordination of centrally-held data along with individual observations
- Better advice and guidance around the Year 1 Phonics Check
- Better access to easily-administered 'screening' assessments and a clearer policy about how information is shared with colleagues and parents.
- Training for all teachers, at all levels, so that they can identify signs of dyslexia-SpLD and know what to do in terms of further assessment and advice.

Dyslexia Action's 2013 *Policy and Practice Review on Dyslexia and Literacy Difficulties* **(Dylsexia Action, 2013)** collated evidence on what represents good practice in providing educational support to children and young people. The four key elements of good practice were identified as:

- A whole school ethos that respects individuals' differences, maintains high expectations for all and promotes good communication between teachers, parents and pupils.
- Knowledgeable and sensitive teachers who understand the processes of learning and the impact that specific difficulties can have on these.
- Creative adaptations to classroom practice enabling children with special needs to learn inclusively and meaningfully, alongside their peers.
- Access to additional learning programmes and resources to support development of key skills and strategies for independent learning.

A regularly updated review on the efficacy of intervention schemes (Brooks, 2016) looks at over 60 interventions used in the UK across secondary and primary schools. The following overall conclusions, with implications for practice, were made:

Conclusion	Implication
Ordinary teaching ('no treatment') does not enable children with literacy difficulties to catch up	Although good classroom teaching is the bedrock of effective practice, most research suggests that children falling behind their peers need more help than the classroom normally provides. This help requires coordinated effort and training.
Schemes for improving writing are few, and Grammar for Writing has great potential.	Provided they receive continuing support, children who make these gains should be better able to cope with the secondary curriculum.
Schemes for children who struggle with spelling work best when highly structured.	Children with spelling problems need schemes tailored to their preferred ways of learning and delivered systematically 'little and often'. Such schemes work particularly well for enabling children to grasp relatively regular patterns of spelling.
Work on phonological skills for reading should be embedded within a broad approach.	Phonics teaching should normally be accompanied by graphic representation and reading for meaning so that irregular as well as regular patterns can be grasped. Children with severe difficulties in phonological skills, or using English as an additional language, may need more 'stand-alone' phonics teaching to support their speaking and listening.
Children's comprehension skills can be improved if directly targeted.	Engaging the child in exploring meaning embeds the relevance of reading for life, expands vocabulary and broadens the range of texts. Children falling behind their peers need both carefully structured reading material and rich, exciting texts.
ICT approaches work best when they are precisely targeted.	The mediation of a skilled adult is essential to ensure technologically driven schemes meet children's needs. Time needs to be allocated effectively so that the diagnostic tools of programmes can be used for each child appropriately.
Large-scale schemes, though expensive, can give good value for money.	When establishing value for money, long-term impact and savings in future budgets for special needs must be considered, particularly when helping the lowest-attaining children.
Where Teaching Assistants can be given appropriate training and support, they can be very effective.	TAs need skilled training and support to maximise impact. A school needs to manage them so that feedback to classroom teachers is effectively and regularly given.
Good impact – sufficient to at least double the standard rate of progress – can be achieved, and it is reasonable to expect it.	If the scheme matches the child's needs, teachers and children should expect to achieve rapid improvement. High expectations are realistic expectations in most cases.

10 Learning disabilities

10.1 Background

Learning disabilities (LD) have a fundamental effect on the way people learn, understand and communicate. Someone with a learning disability will usually have an IQ of 70 or less, depending on the severity of their condition.

People with learning disabilities have significantly poorer health than their non-disabled peers. **They are four times more likely than the general population to die of preventable causes.** They are more likely to have mental health conditions such as psychiatric disorders, conduct disorders or schizophrenia. Respiratory disease, vision impairment and musculo-skeletal problems are also much higher in people with LD than the general population (Prasher & Routhu, 2016). Conditions such as epilepsy and cerebral palsy are also common.

Health outcomes determined by other factors which have a lifelong impact are also affected (Public Health England, 2015). For example, children with learning disabilities are more likely than their non-disabled peers to:
- become poor and remain in poverty
- live in rented housing, overcrowded housing or housing in disrepair;
- be registered for physical abuse, sexual abuse, emotional abuse, and/or neglect.

10.2 What do we know nationally?

- Public Health England estimates that 2% of people in England have a learning disability (Public Health England, 2015).
- By comparison, 0.44% of GP patients are recorded as having a learning disability. This fits the idea of a 'hidden majority', that many adults with learning disabilities are not known to health and social care.
- Recorded prevalence among school-age children is much higher. 4% of children are known to schools as having a learning disability

Prevalence by demography

- **Gender:** The female-to-male ration of school-aged children receiving SEN support for LD (Moderate, Severe or Profound & Multiple) is 1:1.5. For children with a statement of SEN or EHCP, the ratio is 1:1.8. These are narrower than the average gender ratios for SEN support and statements/EHCPs: respectively 1:1.8 and 1:2.7.
- **Ethnicity:** This group makes up on 30% of school-age children generally and school-age children receiving SEN support for LD.
- **ESOL:** Children known or believed to have a first language other than English make up 14.3% of the general school population. However, they are disproportionately represented in the LD population:

Table 1: Percentages of school-aged children with learning disabilities whose first language is not English

| First language other than English	Moderate LD	Severe LD	Profound & Multiple LD	Any SEN
SEN support	18.6%	23.2%	33.3%	16.1%
Statement of SEN or EHC Plan	11.6%	18.1%	24.4%	14.1%

Source: DfE Statistics*: *Special Educational Needs*

- ➤ **Free School Meals:** All children with SEN are almost twice as likely to be claiming free school meals as the general school population (27.2% vs 14.3%). It is even more likely in children with LD: 30.4% are eligible. This is the second highest proportion after Social, Emotional & Mental Health Needs.

10.3   What do we know locally?

- ➤ There are 180 children and young people aged 0-25 with learning disabilities known to GPs within the West London clinical commissioning group (November 2017).
- ➤ **Gender:** 68% of those known to GPs are male and 32% are female Learning disabilities is the second highest proportion of social care cases in Kensington and Chelsea amongst children in need aged 0-17.
- ➤ Nearly half (42%) of social care cases for people aged 18-25 are for learning disabilities support
- ➤ In 2014/15 Kensington and Chelsea had the second lowest recorded prevalence for learning disabilities in London.
- ➤ In 2017 Kensington and Chelsea has less than half the percentage of pupils with learning disabilities than inner London and England.
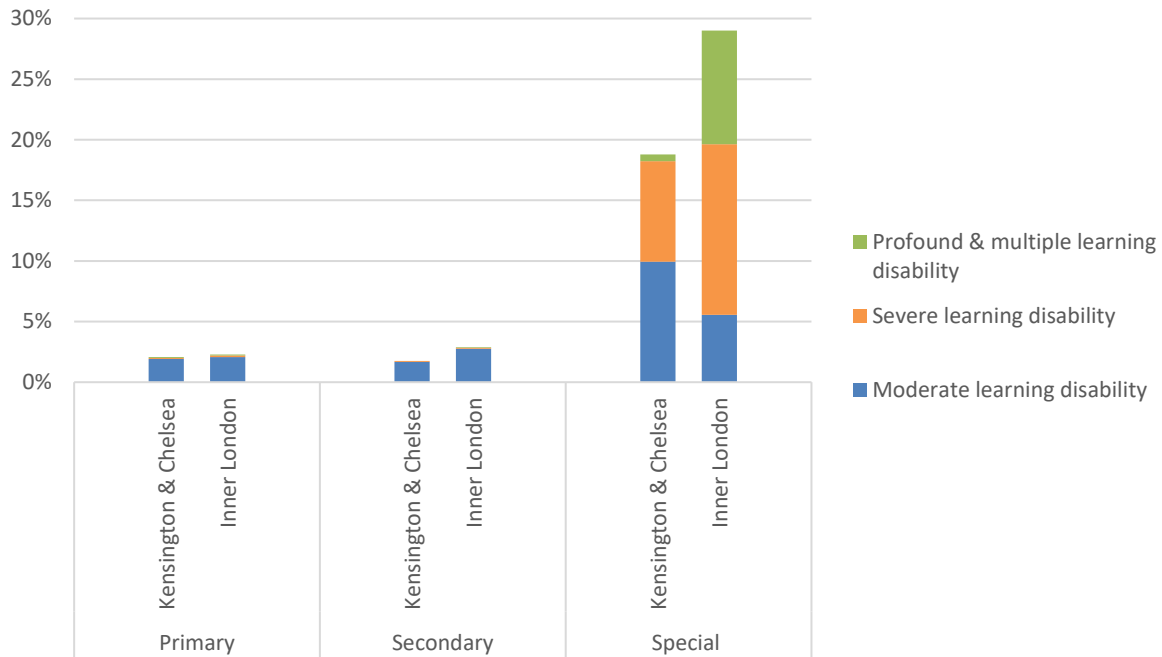
Figure 31: Percentage of all pupils that have learning disabilities
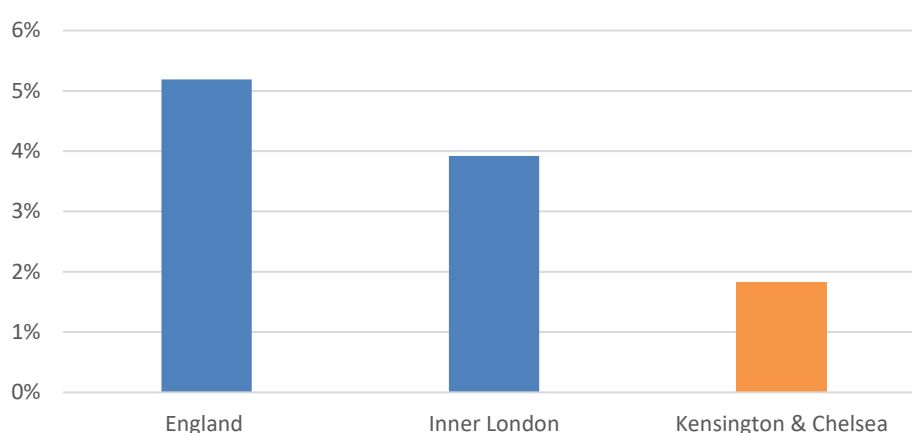
Source: DfE - Special educational needs in England, January 2017, Schools, pupils and their characteristics: January 2017

- There is a significantly higher proportion of children in special schools with learning disabilities than in primary or secondary mainstream schools, suggesting more children are catered for in special schools. This is similar to inner London proportions
- Kensington and Chelsea have less pupils with profound and multiple learning disabilities than inner London

Figure 32: Percentage of pupils in each school with learning disability by type

Source: DfE - Special educational needs in England, January 2017, Schools, pupils and their characteristics: January 2017

Trends

Since 2015, children receiving support for SEN are also counted in these statistics; previously, only children with School Action, School Action Plus or statements of SEN were included. Hence, numbers from 2015 onwards are not comparable. However, it is noticeable that between 2010 and 2014, the proportion of children identified as having LD fell from almost 30% to just over 25%. Numbers in real terms also fell. This could be due to re-categorising the child's diagnosis. The Council for Disabled Children indicates that many children who are now described as having ASD would have previously been labelled as having MLD or SLD in the past.

Numbers of children recorded as having a moderate learning disability rose significantly between 2015 and 2016.

Figure 33: Percentages of school-aged children receiving SEN support, who have learning disabilities 2010-2016

*Note that percentages displayed here are percentages of **children receiving support**, not school population as a whole.*
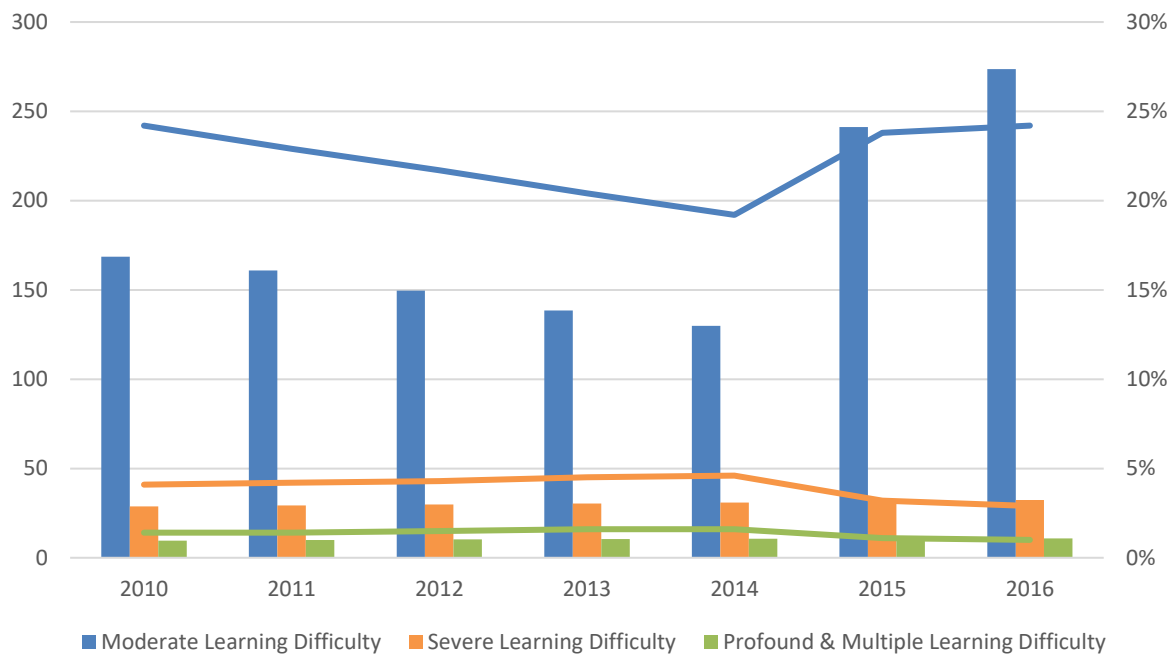
Source: DfE Statistics: Special Educational Needs

10.4 What works?

NICE have developed guidance for the support and management of children with challenging behaviour and learning disabilities (NICE, 2015). Key points on best practice include.

- A focus on working in partnership with children and young people who have a learning disability and their family members or carers.
- GPs should offer an annual physical health check to children, young people and adults with a learning disability in all settings,

The Learning Disabilities Good Practice Project (Hough, 2013) identified the following components of good practice:

➢ People working together
➢ Looking at people' strengths and skills
➢ Helping people live in the community
➢ Services working together

Service models

In 2015 the Local Government Association, Association of Directors of Adult Social Services (ADASS) and NHS England published a service model structured around nine core principles and describing a range of services and supports that should be in place within any local area.

The starting point for the model is the principle that everyone should have access to support that is based on individual need. The aim should be to provide care and support that will improve the person's quality of life which will involve multi-disciplinary working.

Figure 34: Service model for people with a learning disability who display behaviour that challenges.
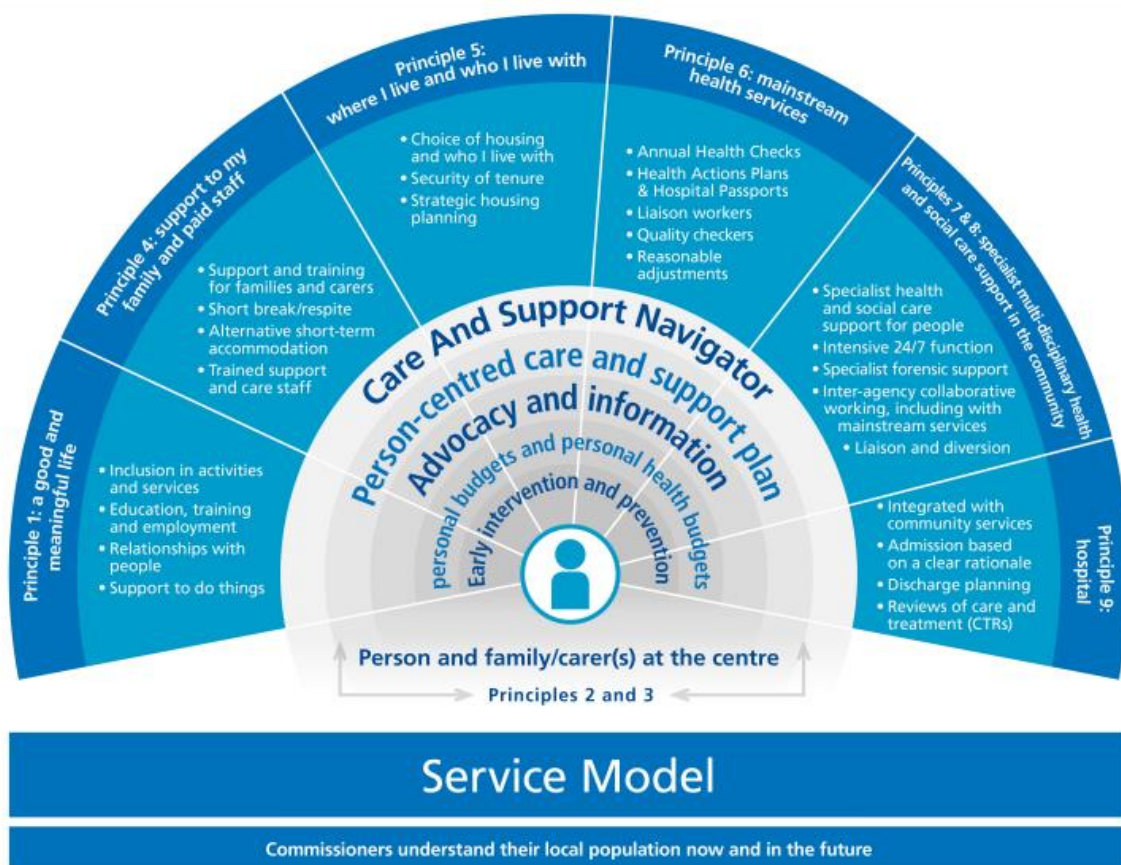
Source: NHS England

Professionals view

A workshop with local professionals from Children's Services and health (see appendix 1) identified a general inequity in services as schools buy and provide different services to their pupils. It was also stated that there is a lack of flexible family support for children with LD.

11 Autism

11.1 Background

Autistic spectrum disorder (ASD) is defined by the NHS as: 'a condition that affects social interaction, communication, interests and behaviour'[11]. It is usually symptomatic before the age of three and occurs in an estimated 1% of the population, more often in boys than girls (although it is suspected that girls may be under-diagnosed). Around a third of people with a learning disability also have ASD, (Emerson & Baines, 2010) (Brugha, et al., 2012). ASD comprises Autism, Asperger syndrome and pervasive development disorder not otherwise specified (PDD-NOS).

11.2 What do we know nationally?

➢ Autistic people are at higher risk of depression and anxiety, neurological conditions (particularly epilepsy), diabetes and heart disease.
➢ ASD in childhood seems to place children at higher risk of a range of conditions including asthma, eczema, food allergies, chronic severe headaches and chronic diarrhoea or colitis (Schieve, et al., 2012).
➢ Early death is a serious issue among people with autism.
• A greater proportion of single people were assessed with ASD than people of other marital statuses combined. This was particularly evident among men.
• Prevalence of ASD was inversely associated with educational qualification, particularly among men. The rate for men was lowest among those with a degree level qualification and highest among those with no qualifications (Brugha, et al., 2009).

11.3 What do we know locally?

➢ There are **684** children and young people aged 0-25 registered with their GP with autism, equivalent of 1.1% of the CCG 0-25 population, however this is said to be an undercount
➢ Gender: 80% male and 20% female, this imbalance is in line with the national prevalence rate

The number of pupils who go to school in the borough with autistic spectrum disorder (a different cohort than the GP population above due to age, pupils attending schools from outside the borough, and private schools not included in the pupil count):

➢ 113 in primary school (10.7% of children with SEN, slightly below the inner London average of 9.7%)
➢ 50 in secondary school (10.4% of children with SEN, above the inner London average 6.9%))
➢ 23 in special primary and secondary schools (24% of children with SEN, lower than the inner London average at 44.3%)

Sources: DfE Statistics: Special Educational Needs

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[11] NHS Choices. *Autistic spectrum disorder* https://www.nhs.uk/conditions/autism/ (accessed 28 June 2018)

11.3.1 Future trends

From 2008-2012 there were 50% more children with ASD in London, but in the three boroughs there were 91% more (Department of Education, 2012). From 2012/13 to 2016/17, of the children who both go to school and live in the borough, there was a 67% increase of children with ASD.

If prevalence remains constant, the absolute number of people with ASD will continue to increase in the coming decade in line with population growth, generating a larger absolute burden on the national and local health economy.

Using the GLA pupil roll projections and percentage increase between 2013 and 2017, projections suggest numbers of children with ASD who go to primary school and live in the borough will increase. However, this crude projection method can provide an indication of a possible future outcome based on previous increases, but cannot say for certain that this will be the increase in prevalence.

Figure 35: Projected increase in numbers of children in who go to school and live in Kensington and Chelsea
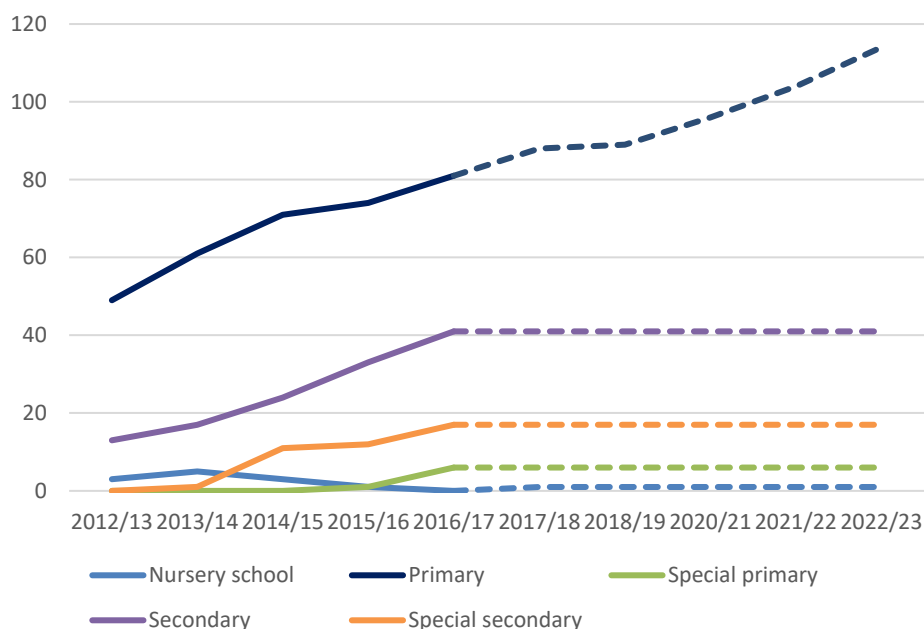
Source: GLA pupil roll projections and school census 2013-2017, School place planning team, Children's Services

Whilst there is uncertainty around the prevalence trends, consistent growth in the population both locally and nationally will lead to an increase in the absolute number of children and young adults with ASD.

11.4 What works?

NICE have developed guidance for the support and management of under 19s with ASD (NICE, 2013). This provides guidance on general principles of care, interventions for core features of autism, specific interventions for behavioural difficulties, interventions to be avoided and the transition to adulthood.

ASD is complex hence there are a range of educational and behavioural programmes for children with ASD. The National Autistic Society outlines the various strategies and approaches to managing children with ASD, but there are four key themes that are incorporated in these approaches:

- **Improving communication skills** – developing alternative ways of communicating with confidence given speech and language skills can be impaired with this condition
- **Social interaction skills** – understanding other people's feelings and responding appropriately
- **Imaginative play skills** – encouraging 'pretend play'
- **Academic skills** – developing traditional skills required to progress with education such as reading, writing and arithmetic

The team responsible for the child's care and management of ASD should be multi-disciplinary coordinated and led by a key worker who is responsible for the management of their condition, as well as transition from child to adult care services. The team should encompass most of the below:

- a pediatrician
- mental health specialists, such as a psychologist and psychiatrist
- a learning disability specialist
- a speech and language therapist
- an occupational therapist
- education and social care services

Families and service user views

In addition to the feedback incorporated into this JSNA from local parents and service users, a number of recurring issues raised by families and service users has been identified from the literature:

- Importance of having relevant information about the diagnosis, what to expect, and when to expect care input, from the outset of diagnosis is helpful and reduces anxiety amongst patients and families. This includes information with definitions of common terms and an understanding of 'who is who' and their responsibilities in the ASD care pathway.
- Patients and carers want to be and feel listened to; to be acknowledged as expert stakeholders because of their first hand experience regarding their own condition, or that or the person they are supporting.
- Carers and families valued the opportunity (and information providing this) to meet with other carers both socially and as a support group to share in learned experiences and develop a support network.
- There is a general concern that support is often just available to those in crisis, whereas this support should be available throughout life also acting pre-emptively rather than being reactive.
- The lack of a reliable and defined pathway for young people transition out of children's services creates anxiety in service users and carers.

Professionals view

- A need for providing more placements closer to home for those with complex needs for children with severe learning difficulties and/or autism
- General lack of resource and placements
- A rationalised and effective local offer for occupational therapy that support equitable access to provision across the three boroughs is required
- Current service provision lacks an evidence-based local offer based on a clearer understanding of what works and value for money
- More services available than most professionals (and parents and children) know about. Information is key. We need to provide information as to what services there are and how to access it.
- The availability of and access to services isn't as transparent to parents as it could and should be. This is highlighted particularly during the lengthy gap between diagnosis and support.
- Parents feel there is a lack of support in children pre-nursery. This early years gap isn't just 'pre-diagnosis' is often post-diagnosis but pre-nursery. This is variable by borough.
- There is a lack of joined up conversations across the pathway. We need to reduce 'clunkiness' especially in transition points i.e. 0-5 to 5-11 etc.
- Waiting times for services are too long.
- Gap in service provision for those without EHCs, included those with Autism+/- challenging behaviour but without learning disabilities
- Lack of clarity or transparency on care availability and options for post 16 and 19 year olds leads to anxiety in younger teenage years and their families.

+ Multi-disciplinary working is a real positive when done well.
+ Joint supported employment strategy encompassing adult social care and public health is a real positive

12   Physical Disabilities

12.1   Background

The last ten years has seen an increase in the prevalence of severe disability and complex needs due to better survival rates of preterm babies and children with severe illness (Pinney, 2017) .

Children with long-term disabilities are a diverse group. Some will have highly complex needs requiring multi-agency support across health, social services and education. Others will require substantially less support, although nevertheless have a long-term disability.

Disabilities are usually identified by the medical profession, and involve a physical or mental impairments which has a substantial and long-term adverse effect on your ability to carry out normal day to day activities.

A 2016 report by The Council for Disabled Children (Pinney, 2017) highlights that at present there appears to be no routinely published national health data on disabled children which contributes to a widespread lack of awareness and policy attention, which in turn undermines the potential for forward planning and intelligent commissioning of specialist provision. Although we do not have a clear picture of this group, a number of national studies give cause for concern.

### 12.2   What do we know nationally?

National health and life outcomes:

➢ Disabled children and young people currently face multiple barriers which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education.

➢ 29% of disabled children nationally live in poverty.

➢ The educational attainment of disabled children is unacceptably lower than that of non-disabled children and fewer than 50% of schools have accessibility plans.

➢ Disabled young people aged 16-24 are less satisfied with their lives than their peers and there is a tendency for support to fall away at key transition points as young people move from child to adult services.

➢ Families with disabled children report particularly high levels of unmet needs, isolation and stress.

➢ Only 4% of disabled children are supported by social services. A report by the Audit Commission in 2003 found that there was a lottery of provision, inadequate strategic planning, confusing eligibility criteria, and that families were subject to long waits and had to jump through hoops to get support.

12.3   What do we know locally?

➢ There are **94 children and young people** aged 0-25 registered with a GP in the West London CCG boundary with physical disabilities, 0.1% of the CCG 0-25 population
➢ **Gender:** 59% male and 41% female)
➢ Majority of children and young people with physical disabilities in Kensington and Chelsea and in their 20s

Figure 36: Percentage of all pupils with SEN, whose primary need is physical disabilities
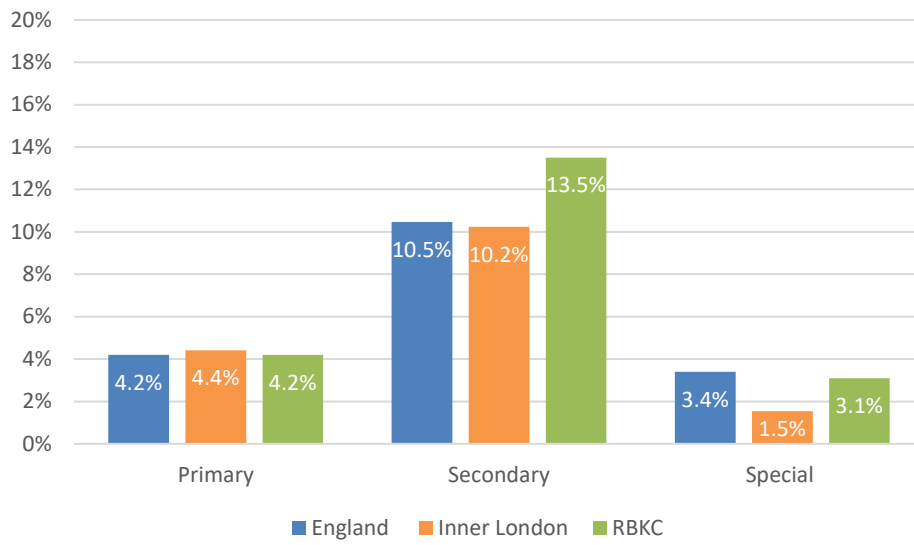
Source: DfE Special educational needs in England: January 2017

12.4 Sensory impairments

12.4.1 Visual impairment

Visual loss or impairment in childhood or adolescence can significantly impair their physical, emotional and social development. Around half the children receiving support from visual impairment services may have additional disabilities, and this proportion is likely to be even higher for children with severe visual loss or blindness.

In a study by Rahi and Cable (Rahi & Cable, 2003), 77% of children newly diagnosed with severe visual impairment or blindness had additional non-ophthalmic disorders or impairments. A re-analysis of the 1989 Office of Population Censuses and Surveys (OPCS) child disability survey showed that children were likely to either have a mild to moderate visual impairment with few other disabilities, or to have visual impairments of a more severe nature, along with several other disabilities also of a severe or profound nature.

There is an increased rate of severe sight problems and blindness in children from ethnic minorities, as well as an association with socio-economic deprivation. These two factors may also be correlated, although with certain ethnic groups

 ➢ There are 128 children and young people aged 0-25 with a visual impairment known to their GP in the CCG boundary, 0.3% of the CCG 0-25 population
 ➢ Gender is split equally: 51% male and 49% female
 ➢ 4% of social care cases of the Children's Disability Team are for visual impairment
 ➢ 0.5% of primary pupils with SEN, 1.9% of secondary pupils with SEN, and 0% of special school pupils with SEN have visual impairment as their primary need

Figure 37: Proportion of children and young people with visual impairment by level of impairment

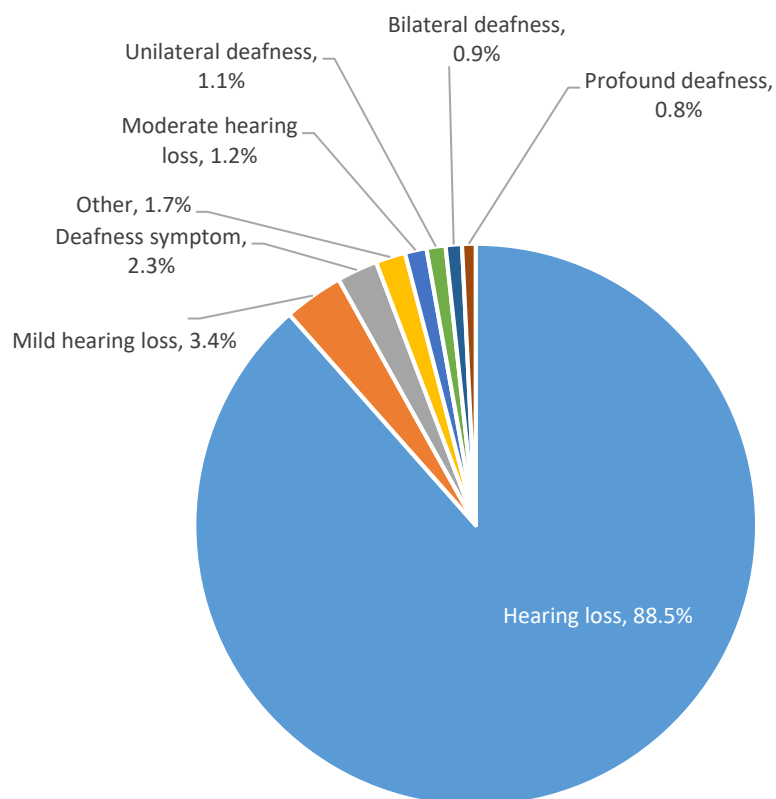Source: DfE Special educational needs in England: January 2017

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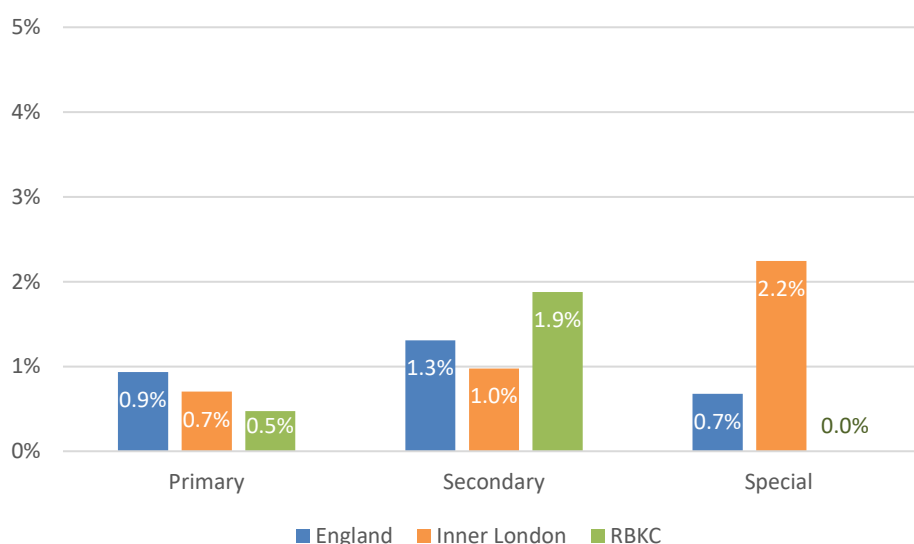
12.4.2 Hearing impairment

Hearing impairment causes delay in speech and language development and thereby causes learning difficulties that impact negatively on academic achievement, and employment opportunities later in life. Children with hearing impairment often report feeling socially isolated and so it also has an impact on their mental wellbeing

The earlier hearing loss occurs in a child's life, the more serious the effects on the child's development. If the problem is identified early and interventions put in place, the impact can be reduced.

➢ There are 622 children and young people aged 0-25 with a hearing impairment known to their GP within the CCG boundary, 1% of the CCG 0-25 population
➢ The picture is similar for male and female, with the gender split 51%/49% respectively
➢ 1% of social care cases of the Children's Disability Team are for hearing impairment
➢ Majority of children and young people with a hearing impairment have hearing loss, with small percentages with profound hearing loss and deafness.

Figure 38: Proportion of children and young people with hearing impairment by level of impairment

Unilateral deafness, 1.1%
Bilateral deafness, 0.9%
Profound deafness, 0.8%
Moderate hearing loss, 1.2%
Other, 1.7%
Deafness symptom, 2.3%
Mild hearing loss, 3.4%
Hearing loss, 88.5%

➢ 1.3% of primary pupils with SEN, 1.7% of secondary pupils with SEN, and 1% of special school pupils with SEN have hearing impairment as their primary need

Figure 39: Percentage of all pupils with SEN, whose primary need is hearing impairment
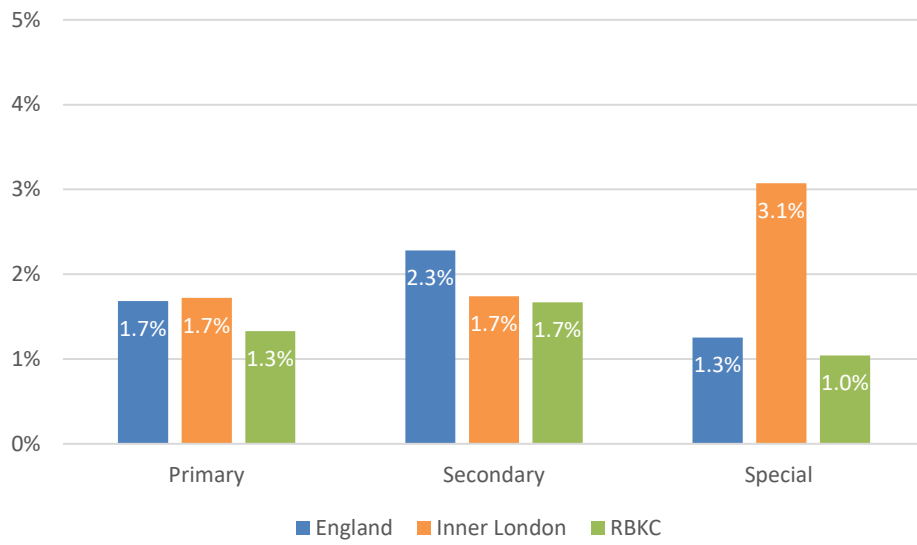
Source: DfE Special educational needs in England: January 2017
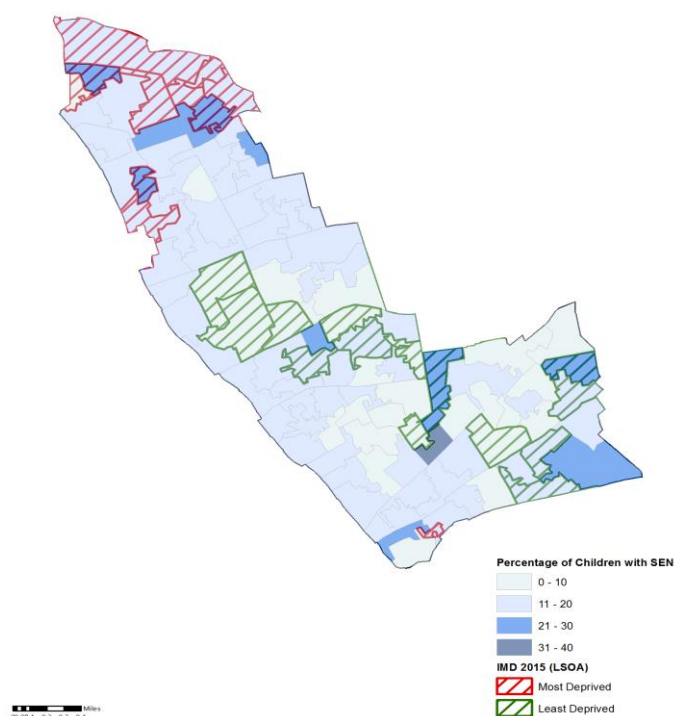
13 Long term health conditions

Poor health in childhood and adolescence can have a significant impact on overall life chances. A significant percentage of local children and young people have a long term physical health condition, illness or disability. We also know that many children and young people who have SEN also have a disability. This can impact on their education, general health and wellbeing.

Figure 40: Children with health specific special educational needs and disabilities, cross referenced with most and least deprived areas

Source: System one and QOF data, West London CCG, November 2017 and Index of Deprivation 2015

Asthma, type 1 diabetes and epilepsy are the most common long-term physical health conditions in children. The majority of children diagnosed with these conditions will have their needs met in schools in line with the "Supporting pupils with medical conditions at school" guidance from the Department for Education[12]. They will not require special educational provision and therefore should not viewed as CYP with SEND. However, in some instances there may be an overlap between students with SEN

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[12] Department for Education. *Supporting pupils with medical conditions at schools* https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3 (accessed 28 June 2018)

and students with a medical condition or the severity and complexity of the child's long term condition may be disabled under the Equalities Act, 2010 and may require special educational provision.

13.1   Asthma

- ➢ Of all children and young people aged 0-25 registered with a GP within the clinical commissioning group boundary, there are 1,704 children and young people recorded as having asthma, 2.69% of the CCG 0-25 population (56% male and 44% female).
- ➢ Pollution can trigger asthma symptoms and all inner London boroughs, including Kensington and Chelsea, have high levels of pollution

Asthma is the most common condition in childhood. Socio-economic factors are associated with asthma prevalence, severity and hospitalisation. For example, indoor dampness and mould exacerbates asthma, and so it is correlated to deprivation.

A child with asthma may not have special educational needs, but will still have rights under the Equality Act 2010. Each child is assessed in order to identify their needs.

13.2   Diabetes

- ➢ Of all children and young people aged 0-25 registered with a GP within the clinical commissioning group boundary, there are **196 children and young people** recorded as having diabetes (51% male and 49% female), 0.3% of the CCG 0-25 population.
- ➢ The UK has the world's fifth highest rate of Type 1 diabetes diagnosis in children aged up to 14, with 24.5 incidences per 100,000[13].

Type 1 Diabetes is a serious chronic condition, mostly diagnosed in childhood. The condition can have a significant impact on a child's daily activities, including schooling and learning. Some children with Type 1 diabetes will have an Education, Health and Care plan or statement of special education needs

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[13] Diabetes UK. *List of countries by incidence of Type 1 diabetes ages 0 to 14.* https://www.diabetes.org.uk/About_us/News_Landing_Page/UK-has-worlds-5th-highest-rate-of-Type-1-diabetes-in-children/List-of-countries-by-incidence-of-Type-1-diabetes-ages-0-to-14 (accessed 28 June)

in place in order to meet their needs. The level of support required for children with Type 1 diabetes will differ depending on their experience[14].

Case study: young people's Diabetes Support Project, The Well Centre, Lambeth

The Well Centre in Lambeth, in partnership with King's Health Partners, is running a trial project to support young people age 14-21 with type 1 diabetes through education and youth work to support young people to manage their health by:

- Providing youth work support on a 1-to-1 basis as well as group workshops
- Providing a structured education programme designed with young people with type 1 diabetes.

13.3 Epilepsy

Epilepsy is one of the most common neurological disorders. In many cases, no cause of epilepsy is found. In others, epilepsy can be caused by infections that can damage the brain such as meningitis, problems during birth that cause a baby to be deprived of oxygen, or some parts of the brain not developing properly. There are many clinical manifestations, ranging from otherwise well children with occasional seizures, to children with complex medical co-morbidities and considerable disability. Epilepsy is more common in people with learning or intellectual disabilities, and in the most socially deprived areas compared to the least socially deprived (Joint Epilepsy Council of the UK and Ireland, 2011).

A child has special educational needs if they have learning difficulties or disabilities that make it harder for them to learn than other children of the same age. Epilepsy is a very individual condition, therefore how it affects a child's education can vary[15].

> ➢ Of all children and young people aged 0-25 registered with a GP within the clinical commissioning group boundary, there are 60 as having Epilepsy

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[14] Diabetes UK. *Diabetes in schools – responsibilities of SENCOs/ Additional Needs Coordinators/ Inclusion Managers*. https://www.diabetes.org.uk/Guide-to-diabetes/Your-child-and-diabetes/Schools/School-staff/Responsibilities-SENCOs-Additional-Needs-Coordinators-Inclusion-Managers (accessed 28 June 2018)
[15] Epilepsy Society: *School, education and epilepsy* https://www.epilepsysociety.org.uk/school-education-and-epilepsy (accessed 28 June 2018)

14 Social Care

14.1 Background

A cohort of children and young people with physical and learning disabilities are likely to be in receipt of care services from the local authority in addition to support with education and health.

Continuing care packages for children are available when a child or young person (under the age of 18) has needs arising from a disability, accident or illness that cannot be met by existing universal or specialist health services alone, such as cancer or congenital heart disease. Where a child or young person has a special educational need or disability, which will often be the case, the CCG and local authority should endeavour to coordinate the assessment and continuing care package as part of the Education, Health and Care plan (Department of Health, 2016).

The needs may be so complex that they are not able to be met close to the young person's home, and so a residential placement may be required. The CCG that is responsible for the young person will assess and determine their level of need. A multi-agency understanding of a child's needs is important – for example if they have continuing care needs they may well also have special educational needs. The assessment process for an EHC plan and continuing care should be similar, and some may need a health intervention or a social care intervention. Personal health budgets can be used where requested by the child of their family.
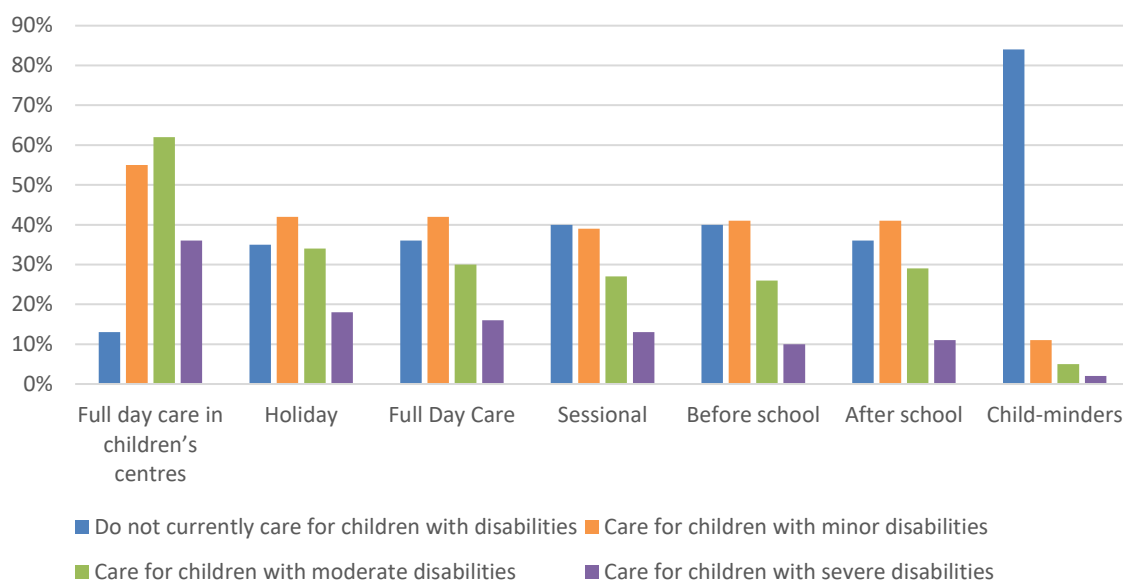
14.2 What do we know nationally?

14.2.1 Childcare provision for children with SEND

Nationally, early years providers do not always provide for children with disabilities or cater well to children with SEN, and the rates differ across different types of providers.

- **Full day cares in children's centres** are the setting most likely to care for children with disabilities.
- **Child-minders** are the least likely to, but it is unclear whether that is because most have not had the opportunity to do so.

Figure 41: Proportion of providers caring for children with disabilities, 2013

Legend:
- Do not currently care for children with disabilities (blue)
- Care for children with minor disabilities (orange)
- Care for children with moderate disabilities (green)
- Care for children with severe disabilities (purple)

Children with disabilities are less likely to participate in mainstream settings as they get older:

- The majority of nurseries are attended by children with all levels of disabilities
- 12% of primary schools are attended by children with severe disabilities compared to 49% of nurseries.

## 14.3 What do we know locally?

14.3.1 Children in need

In Kensington and Chelsea, 27.5% of children in need are receiving SEN support and 17.2% of children in need have a statement of SEN or EHC plan.[16] This compares to 25.5% of Children in Need receiving SEN support and 24.1% with a statement of SEN or EHC plan in London.

Children in need are defined as children who need local authority services to achieve or maintain a reasonable standard of health or development, or to prevent significant or further harm to health or development, or are disabled.

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[16] Local Government Association Local area SEND report (accessed 28 June 2018)

**Figure 42: Percentage of children in need receiving SEN support, or with a statement of EHC plan 2015/16**
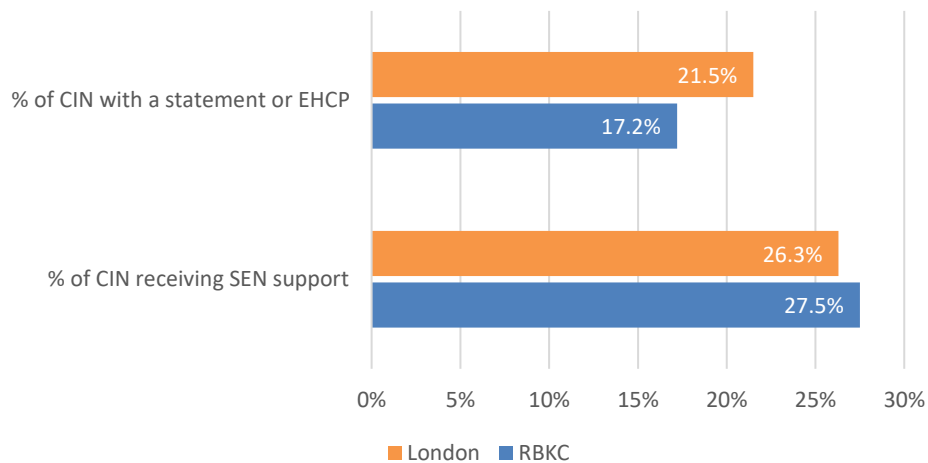
Source: Department for Education, Characteristics of Children in Need in England: Outcomes

14.3.2 Looked after children

Looked after children are defined as those looked after by the local authority for one day or more. In Kensington and Chelsea, 23% of looked after children are on SEN support, compared to 28.4% in London. There are 41.2% of looked after children in Kensington and Chelsea that have a statement of SEN or EHCP, compared to 30.5% in London.

Figure 43: Percentage of looked after children with a statement or EHC plan, or receiving SEN services (2015/16)
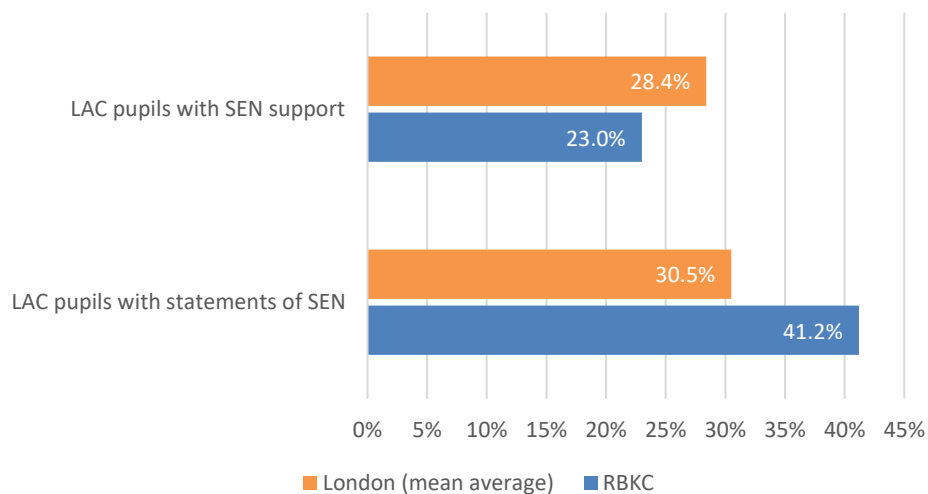

Source: Department for Education, Outcomes for Children Looked After by Local Authorities in England

14.3.3 Disabilities

Having a disability does not mean the child will automatically be known to social care. Therefore, social care data provides a snapshot view of a small subset of the borough's population.

➢ The Disabled Children's team worked with 99 children in need in 2015/16 and 73 in 2016/17. As of September 2017/18, the team were working with 97 children in need.
➢ 10.6% of children in need have a disability[17]
➢ As at 31st March 2017, there were more boys than girls receiving social care support from the Disabled Children's Team.
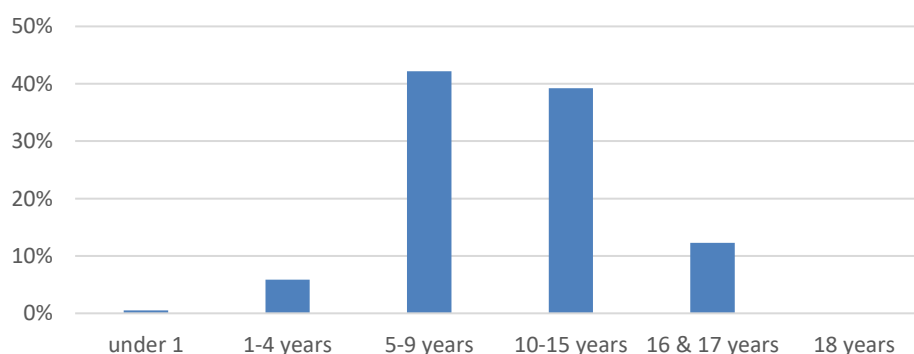
Figure 44: Proportion of males and females working with Children's Disabled Team as at 31st March 2017
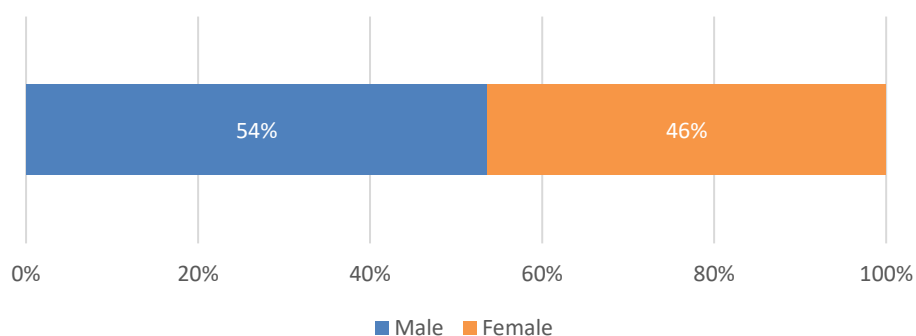
Source: Kensington and Chelsea's Children's Services Business Intelligence, November 2017

➢ The largest proportion of children receiving support from the Disabled Children's team are 5-15 year olds

Figure 45: Proportion of children in need receiving support from the Children's Disabled Team, by age as at 31st March 2017

Source: Kensington and Chelsea's Children's Services Business Intelligence, November 2017

➢ The largest proportion of social care cases are due to behaviour, learning disabilities, autism and communication needs in Kensington and Chelsea

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[17] Department for Education, *Characteristics of Children in Need in England for year 2016/17.*
https://www.gov.uk/government/statistics/characteristics-of-children-in-need-2016-to-2017 (accessed 28 June 2018)

Figure 46: Proportion of social care cases in Kensington and Chelsea by type as at 31st March 2017
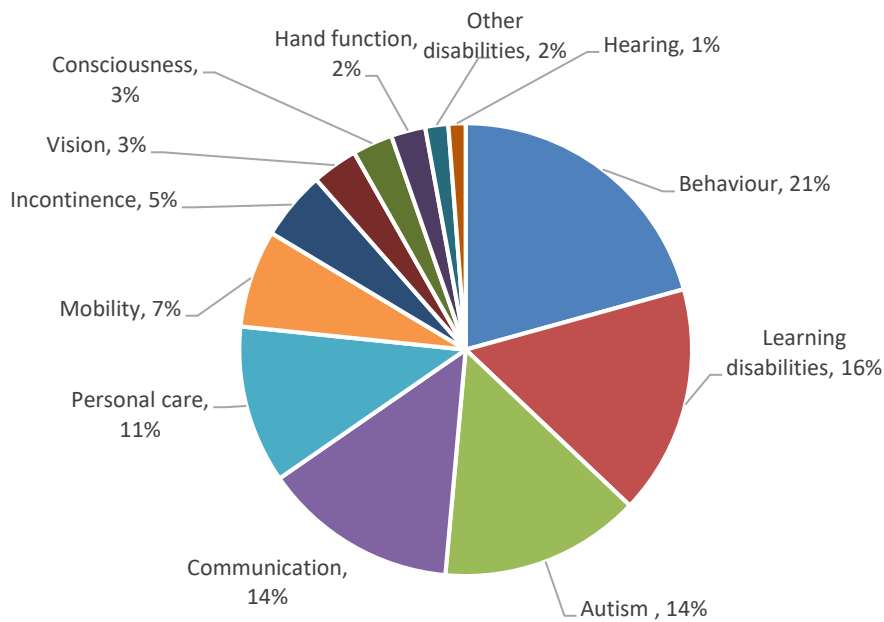
14.3.4 Care needs of young people age 18-25:

Children with learning or physical disabilities are likely to transition from Children's Services/ paediatric services to adult health and care services. Preparation for transition should start well before age 18.

➢ The majority of 18-25 year olds in Kensington and Chelsea receive social care support for mental health and learning disabilities.

Figure 47: Percentage of social care users in Kensington and Chelsea aged 18-25 by primary support
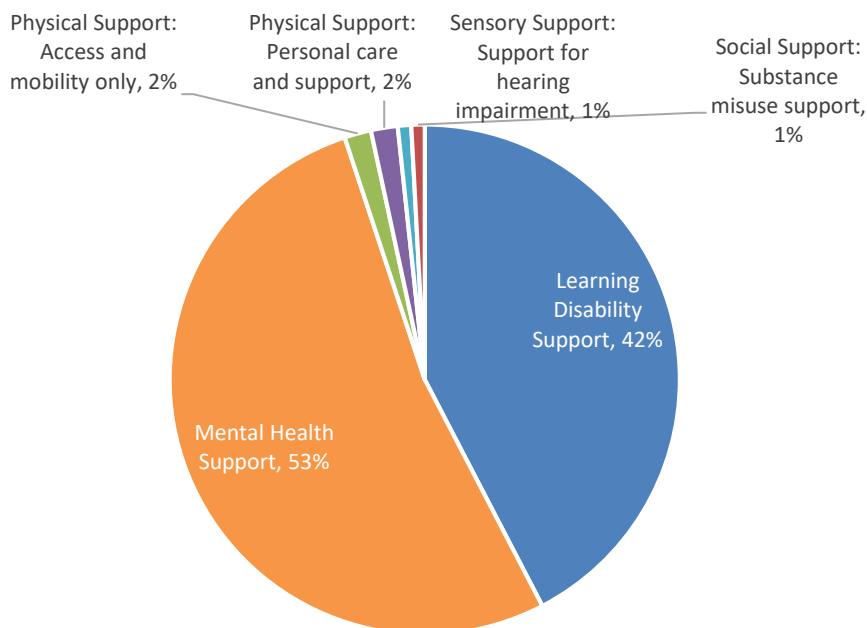
15 Parents and carers of children with complex needs

15.1 What do we know nationally?

Being a parent of a child with a special educational need or a disability or long term condition raises a particular set of challenges and needs. It is a lifelong life-changing experience for a parent, with many parents describing having to adjust to changes depending on the needs of their child as they grow older.

Sartore et al (Sartore, Lagioia, & Mildon, 2013) report that the parents and carers of children with complex needs experience exceptional pressure to meet the emotional and physical needs of the child (or children), while at the same time maintaining family functioning. Parents of children with complex needs often demonstrate poor mental well-being (such as quality of life and life satisfaction) and show signs of psychological distress such as depression, anxiety, or stress.

Caring for children with complex needs can require extensive amounts of time, and can be physically and emotionally demanding. Some parents describe being physical and emotionally overburdened, manifesting as chronic fatigue (Smith, Cheater, & Bekker, 2015).

These demands on the parent or carers time reduces their resources and energy available for other activities such as paid employment, social activities, and hobbies. Family and social relationships can be strained, and parents can be left feeling overwhelmed and isolated. Furthermore, parents often feel that they have an ongoing battle with professionals to ensure that the needs of their child are met, which is exhausting and means that parents often do not feel supported.

The emotional impact on parents is significant. Frank Parkinson (1997) refers to parents of disabled children as 'experiencing trauma' with all the attendant symptoms such as rage, grief, intrusive thoughts, lack of control and anxiety. Many experience grief over the loss of a 'hoped for' baby. Parents can experience 'chronic sorrow' - which can often impact our ability to retain and assimilate information.

If a child has challenging behaviour, this can make social activities difficult, a problem made worse by a lack of understanding in the community of the underlying condition. Parents can feel stigmatized and as a result, they may restrict social activities or may socialise only with other families whose children have a similar diagnosis. In some cases families may be excluded from social gatherings by others.

As the care of children with long-term conditions is provided at home, parents and carers must, by necessity, become experts in their child's condition and in the local health and care systems and interventions. This results in parents trusting their judgement and being able to make decisions and assessments for their child, and feeling empowered to challenge professionals where appropriate. However, this expertise is often not valued.

15.2 What do we know locally?

Two years ago Full of Life, Kensington and Chelsea's Parent Group, carried out a Health Survey with 30 parents known to their service. This was triggered by three mothers being diagnosed with breast cancer within a fortnight of each other. The following highlights the key findings:

- 30% of parents care for more than one person, some care for up to three other people.

- 83% report problems with their joints and back.

- 70% of parents reported an average of 4.5 hours of uninterrupted sleep. Lack of sleep correlates with increased risk of cardiovascular disease, insulin resistance, risk of falling, and dementia.

- 65% of parents reported immune system problems

- 55% of parents have been injured in their caring role due to falling or aggressive behaviour by the child/adult they care for.

- 71% feel depressed and sad despite having medication.

- 36% experience anxiety/panic attacks/OCD/agoraphobia/claustrophobia

- 15% of parents experience confrontational situations on a regular basis

- 83% of parent carers say caring interferes with their own, even basic healthcare

- Parent carers report they have no time to make appointments with Doctors and often have to cancel due to unpredictability of full time caring responsibilities. If parent carers do have treatment, they have no time to heal.

Contact with other parents who have the same experiences is a key strategy to address the emotional impact on carers. Local parent forums are key to ensuring that parents and carers have a meaningful opportunity to be involved in the review, evaluation and shaping of the SEND Local Offer. A series of parent-led focus groups with Full of Life in 2017 has provided an opportunity to identify some key issues and themes that are important to parents and carers.

Key themes identified from these include:

1. The support which children and young people receive in mainstream and specialist settings is variable

   "All schools should be able to support children and young people with medical conditions"

2. The Local Offer requires improvement and should be aligned to a workforce development programme

   "SENCOs need training around Year 9 reviews and links to the Local Offer"

3. The Early Years pathway needs further development

   "More support is needed for families post diagnosis and in learning to navigate the Local Offer"

4. Preparing for adulthood and transition remains a stressful time for young people with SEND and their families

   "Transition – it's one part of the Council to another part of the Council – it needs to be smoother!"

5. Access to health provision and to therapies also needs further collaborative work

   "More clarity as to what parents should expect around SALT (Speech and Language Therapy) as their child progresses through school and on into college"

In Kensington and Chelsea, the following areas were identified as priority themes by the Full of Life Parent Forum:

- The role of the key worker
- Challenge and support around inclusion in mainstream and special provision
- Health and therapies
- Provision and support for children and young people with High Functioning Autism

"Young people with ASD can feel lonely, isolated and misunderstood – which in turn affects behaviours and wellbeing"

The appendices include a summary of feedback from parents and carers in a 'You said, We Will' format

In response to this feedback the Local Authority have begun to address some of these issues through:
- Further development of the Early Intervention pathways
- Development of the SEN Support Toolkit
- Quality assurance of the Local Offer and planned Local Offer Champions
- Maximising the SENCO Forums for priority workforce development activities
- Schools Surgeries between June and October 2017 to re-visit their 'Local Offer' and discuss collaboration going forward

15.2.1 What works?

Research by Smith et al (Smith, Cheater, & Bekker, 2015)found that adaptation and coping were important features of living with a child with a long term condition. This appears to be a dynamic process depending on the changing needs and condition of the child. The majority of parents adapt and cope with living with a child with a long term condition over time.

Family life is often disrupted and relationships can be strained, because of the unpredictability of the child's condition and the need to accompany the child to a range of appointments. However, Smith et al report that this can lead to increased family cohesion as communication among family members often improves through the need to interact daily. The main barrier to maintaining family cohesion was the time needed to meet carer commitments which meant that parents had limited time to spend with each other.

A report by NHS Highland (Edwards, 2013) identified a number of themes as being important in parenting a child with complex needs:

- Individual characteristics or skills
- Family networks and support
- Role of the partner and the nature of the relationship
- Contact with other parents
- Individual practitioners were often regarded as supportive but systems and processes were not considered supportive
- Voluntary organisations
- Spiritual support

A recent review by a team of Canadian researchers (Edelstein, Schippke, Sheffe, & Kingsnorth, 2017) identified the following intervention 'domains' as successful in reducing stress of carers of children with complex needs:
- Care coordination model
- Respite care
- Telemedicine
- Peer and emotional support
- Insurance and employment benefits
- Health and related support

Across studies, there was a wide variety of designs, outcomes and measures used, and there was no conclusive evidence on which intervention was most effective. The authors conclude that multiple interventions may be effective in reducing burdens of care experienced by families of children with complex needs.

16   Appendices

16.1 Appendix 1: Engagement

16.1.1   Launch event: Stakeholder Workshop, January 2017

A workshop was held on 27th January with professionals from the local authorities' Education and Social Care teams as well as Health professionals.

16.1.2   BME Health Forum, March 2017

A workshop was held at the BME Health Forum with third sector organisations who support local BME populations in the three boroughs. The workshop focussed on issues which are specific to BME families with children and young people with SEND.

16.1.3   Full of Life Parent Forum

A series of parent-led focus groups held in 2017 has provided an opportunity to identify key issues and themes that are important to parents and carers.   "You Said, We Will" feedback from parents and carers is described below.

YOU SAID...	WE WILL....
We welcome our involvement in the strategic planning and development of SEND services via the Parent Reference Group and the CFA Quality Assurance Board, but we aren't always sure how our views have been taken into account or acted upon. *Wider consultation with parents including on the Local Offer has been good but needs to coordinated to make best use of our time.*	• Develop better feedback for parent representatives that sets out how their views have influenced decisions about services and who to talk to check on progress. • Review and rationalise the involvement of parents across the CFA Programme.
It isn't clear what we can expect from schools under the new SEN funding arrangements and we sometimes feel we are left as parents to broker this conversation. *For the new SEN Support and EHC Plan approach to work effectively for parents there has to be clear understanding between schools and the local authority about their relative role & contributions, and the confidence/trust to work*	• Work with schools to make sure: o there is up to date SEN Information Report for all schools on the local offer website o they make best use of the wider SEND resources available to them locally to support children in a mainstream setting o review the effectiveness of our commissioned SEN outreach

The joint training of SEN Keyworkers with Full of Life was a positive step but there is still a wide range of variation in the skills & knowledge of individual workers.	• Continue with the fundamental re-organisation of the SEN Team that is currently underway, in recognition of the need to establish a consistent, high quality service with transparent decision making and clear accountability.
The current panel processes can feel quite slow & unresponsive.	• Act on the findings of the current review of panel processes including appropriate delegated authority and improved recording.
Health involvement in the joint EHC assessment has to be the right involvement i.e. someone who has a good (and recent) knowledge of the child or young person.	• Follow up parent's suggestion that individual Health Care Plans attached to the EHC Plan.
Access to Speech and Language assessment & therapy where a child or young person is not eligible for an EHC Plan is harder than under pre CFA arrangements.	• Undertake a whole system review (CCG, Local Authority and individual schools) of current commissioning and provision.

16.2 Appendix 2: Services

Children and young people receive specialist support linked to their special educational needs and / or disability. Where a statement or Education, Health and Care Plan is in place, the provision will be specified.

Due to the cross-over between education, social care and health needs, many of the services outlined are jointly funded by the local authority and Central London clinical commissioning group. There are joint transformational activities taking place that consider the overall pot of funding for the service and collaboratively design future system approaches.

A Local Offer gives children and young people with special educational needs or disabilities, and their families, information about what support services the local authority think will be available in their local area. Every local authority is responsible for writing a Local Offer and making sure it is available for everyone to see.

You can access Kensington and Chelsea's local offer here

Some of the services listed are provided by the council, but others come from external organisations such as health services, voluntary sector organisations, or businesses.

Feedback from young people with SEND in Westminster on the Local Offer indicated that the website needs to have more links to social media, be more visual, and include service opening hours.

16.3 Appendix 3 – Guidance

16.3.1 NICE Guidelines

- Transition from children's to adults' services for young people using health or social care services
- Autism spectrum disorder in under 19s: support and management
- Attention deficit hyperactivity disorder: diagnosis and management
- Antisocial behaviour and conduct disorders in children and young people: recognition and management
- Mental health problems in people with learning disabilities: prevention, assessment and management
- Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

16.3.2 Key guidance

The government sets out a range of guidance materials for schools, colleges and children's services in providing for children and young people with SEND. This is encapsulated in the SEND Code Of Practice for 0 to 25 years, however specific guides are also provided for schools, social care professionals, parents etc. Further guidance is given on subjects such as supported internships, short breaks, and education for children who cannot attend school. Early years provision and the identification of SEND, as it applies to children under primary school age, is discussed in the Early Years guide and statutory framework.

The Learning Disability Transition Pathway Competency Framework was developed by Health Education England and published in October 2016. It is aimed at service providers and addresses the needs of young people with learning disabilities as they move from children's to adults' services.

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