



City of Westminster

# Committee Agenda

Title: **Health & Wellbeing Board**

Meeting Date: **Thursday 24th May, 2018**

Time: **4.00 pm**

Venue: **Room 3.6 and 3.7, 3rd Floor, 5 Strand, London, WC2 5HR**

Members:

Councillor Heather Acton (Chairman)	Cabinet Member for Family Services and Public Health
Dr Neville Pursell	Central London Clinical Commissioning Group
Councillor Nafsika Butler- Thalassis	Minority Group
Mike Robinson	Bi-Borough Public Health
Bernie Flaherty	Bi-borough Adult Social Care
Melissa Caslake	Bi-borough Children's Services
Tom McGregor	Director of Housing and Regeneration
Dr Naomi Katz	West London Clinical Commissioning Group
Olivia Clymer	Healthwatch Westminster
Hilary Nightingale	Westminster Community Network
Dr David Finch	NHS England
Dr Joanne Medhurst	Central London Community Healthcare NHS Trust
Clare Robinson	Imperial College NHS Trust
Maria O'Brien	Central and North West London NHS Foundation Trust
Detective Inspector Iain Keating	Metropolitan Police

**Members of the public are welcome to attend the meeting and listen to the discussion Part 1 of the Agenda**

**Admission to the public gallery is by ticket, issued from the ground floor reception at City Hall from 6.00pm. If you have a disability and require any special assistance please contact the Committee Officer (details listed below) in advance of the meeting.**





**An Induction loop operates to enhance sound for anyone wearing a hearing aid or using a transmitter. If you require any further information, please contact the Committee Officer, Toby Howes, Senior Committee and Governance Officer.**

**Tel: 020 7641 8470; Email: [thowes@westminster.gov.uk](mailto:thowes@westminster.gov.uk)  
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**Note for Members:** Members are reminded that Officer contacts are shown at the end of each report and Members are welcome to raise questions in advance of the meeting. With regard to item 2, guidance on declarations of interests is included in the Code of Governance; if Members and Officers have any particular questions they should contact the Director of Law in advance of the meeting please.

## **AGENDA**

### **PART 1 (IN PUBLIC)**

**1. MEMBERSHIP**

To report any changes to the Membership of the meeting.

**2. DECLARATIONS OF INTEREST**

To receive declarations of interest by Board Members and Officers of any personal or prejudicial interests.

**3. MINUTES AND ACTIONS ARISING**

**(Pages 1 - 20)**

(a) To agree the Minutes of the meeting held on 20 March 2018.

(b) To note progress in actions arising.

**4. PATIENTS AND THEIR CARERS EXPERIENCES OF LIVING WITH LONG TERM HEALTH CONDITIONS IN WESTMINSTER**

**(Pages 21 - 60)**

To consider a report on patients and their carers experiences of living with long term health conditions in Westminster.

**5. CHILDREN AND YOUNG PEOPLE SPECIAL EDUCATIONAL NEEDS AND DISABILITIES JOINT STRATEGIC NEEDS ASSESSMENT**

**(Pages 61 - 146)**

To consider the final draft of the Children and Young People Special Educational Needs and Disabilities Joint Strategic Needs Assessment.

**6. ANY OTHER BUSINESS**

**Stuart Love  
Chief Executive  
17 May 2018**

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**CITY OF WESTMINSTER**

# MINUTES

## Health & Wellbeing Board

### MINUTES OF PROCEEDINGS

Minutes of a meeting of the **Health & Wellbeing Board** held on **Tuesday 20th March, 2018**, Rooms 3.6 and 3.7, 3rd Floor, 5 Strand, London WC2N 5HR.

#### **Members Present:**

Chairman and Cabinet Member for Adult Social Services and Public Health:  
Councillor Heather Acton  
Clinical Representative from the Central London Clinical Commissioning Group:  
Dr Neville Pursell  
Minority Group Representative: Councillor Barrie Taylor  
Bi-borough Public Health: John Forde  
Bi-Borough Adult Social Care: Bernie Flaherty  
Bi-Borough Children's Services: Annabel Saunders (acting as Deputy)  
Clinical Representative from West London Clinical Commissioning Group:  
Dr Naomi Katz (acting as Deputy)  
Healthwatch Westminster: Godwyns Onwuchekwa (acting as Deputy)  
Chair of Westminster Community Network: Hilary Nightingale  
Central and North West London NHS Foundation Trust: Dr Paul Hopper

**Also Present:** Philippa Mardon (Interim Deputy Managing Director, NHS Central London Clinical Commissioning Group) and Jayne Liddle (Director of Integrated Care, NHS West London Clinical Commissioning Group).

#### **1 MEMBERSHIP**

- 1.1 Apologies for absence were received from Councillor Richard Holloway (Cabinet Member for Children, Families and Young People), Councillor Karen Scarborough (Deputy Cabinet Member for Children, Families and Young People), Melissa Caslake (Bi-borough Director of Children's Services), Tom McGregor (Director of Housing and Regeneration), Janice Horsman (Healthwatch Westminster), Dr David Finch (NHS England), Dr Joanne Medhurst (Central London Community Healthcare NHS Trust) and Maria O'Brien (Central and North West London NHS Foundation Trust).
- 1.2 Annabel Saunders (Tri-borough Director of Commissioning), Naomi Katz (NHS West London Clinical Commissioning Group), Godwyns Onwuchekwa (Healthwatch Westminster) and Dr Paul Hopper (Central and North West

London NHS Foundation Trust) attended as Deputies for Melissa Caslake, Dr Philip Mackney, Janice Horsman and Maria O'Brien respectively.

- 1.3 The Chairman welcomed Hilary Nightingale to the Board as the Westminster Community Network's representative, replacing Jackie Rosenberg. It was also noted that Dr Naomi Katz was replacing Dr Philip Mackney as the NHS West London Clinical Commissioning Group Representative.

## **2 DECLARATIONS OF INTEREST**

- 2.1 There were no declarations of interest.

## **3 MINUTES AND ACTIONS ARISING**

### **3.1 RESOLVED:**

That the Minutes of the meeting held on 18 January 2018 be signed by the Chairman as a correct record of proceedings.

- 3.2 The Chairman requested that the suggestion that the Board receive an annual report from the Care Quality Commission on its overall work be included in the Action Plan.

### **3.3 RESOLVED:**

That progress in implementing actions and recommendations agreed by the Westminster Health and Wellbeing Board be noted.

## **4 CHAIRMAN'S VERBAL UPDATE**

- 4.1 The Chairman informed Members that she had attended the Care Awards on 19 March and the event had been a success. The Oral Health Campaign's animation had been screened at primary schools and libraries and had received unanimous positive feedback. The campaign had also received press coverage from Dentistry Today, The Times and the Daily Mail. The Chairman advised that a new programme, Westminster Sings, had been established involving the creation of five new singing groups in areas where there was a higher concentration of people on low incomes. A new choir, Mind in Westminster, had also been set up to help people affected by mental health issues. Another project, My Westminster Silver Neighbours aimed to reduce isolation amongst older residents and a new staff member had been appointed through Open Age to support this project.

- 4.2 The Chairman also advised of plans to hold a facilitated workshop for the Board in May 2018 to identify areas it should focus on and how it can play a more strategic role. The workshop could also be use to help create the Board's Work Plan for the remainder of 2018 and it was intended that the workshop would be facilitated by Chris Bull who had also facilitated a workshop for the Board in May 2017. Finally, the Chairman referred to the Red Cross report on 'Prevention in Action' and commented that the Board should adopt the approach taken in the report and to look at it more closely.

## **5 LOCAL AREA SPECIAL EDUCATIONAL NEEDS AND DISABILITY BRIEF**

- 5.1 Victor Roman (Bi-borough Special Educational Needs and Disability Inspection Preparation Manager) presented the report which summarised the guidance published for the Special Educational Needs and Disability (SEND) Inspection and the preparation being undertaken in the local area for this. Victor Roman advised that the inspection was a Partnership Focus Inspection Type, which would focus on how the local area works together in identifying, assessing and meeting needs. There was no grading given by the outcome of the inspection, which culminated in a report to the Director of Children Services and the most senior officers of the relevant clinical commissioning groups (CCGs), highlighting both the strengths and areas of improvement for the local area. However, where areas for improvement were significant, the local area would be required to submit a Written Statement of Action within 70 working days of receiving the report.
- 5.2 Victor Roman advised that a principle change from previous inspections was that the age range to be looked at had increased from 5 to 19 years to 0 – 25 years. The inspection would take place over 2 weeks and as a partnership inspection involved all agencies interacting with children and young people on Special Educational Needs (SEN) support or with an education health and care plan in the local area. This would include the local authority, the relevant CCGs, early years providers, colleges, health providers, parent partnership and the third sector.
- 5.3 Victor Roman then highlighted the preparation being taken for the inspection by bi-borough partners, including:
- Ensuring that the data is easily available and meaningful
  - Ensuring that the local area has all the required policies and strategies in place, such as the Health and Wellbeing Strategy, the Joint Strategic Needs Assessment and the SEND strategy
  - Ensuring that the right governance and process are in place for the local area
  - Ensuring that the local area has a common understanding of the strengths and areas of improvement for partnership
- 5.4 Victor Roman informed the Board that of around 50 inspections that had taken place nationally since 2016, the key themes the inspectors had focused on included SEN support, preparation for adulthood, joint commissioning arrangements, early years identification and co-production. He concluded his presentation by emphasising the need to demonstrate to the inspectors that the partnership in the local area works effectively at identifying, assessing and meeting needs and improving outcomes for children and young people with SEN and/or disabilities.
- 5.5 During discussions, a Member enquired whether Healthwatch and Black and Minority Ethnic groups had been approached for comments in respect of the inspection preparation. He stated that there needed to be a greater focus on mental health in primary schools and he referred to a primary school in

Queens Park that had received an award for work undertaken in this area. He added that there was also a need for a greater focus on pre-teen mental health. One Member commented that Child and Adolescent Mental Health (CAMHS) Services referrals were often not reported to GPs and there needed to be more effective communication on this. In addition, the Grenfell Tower fire had impacted significantly on CAMHS and she suggested that they should be fed into the inspection. Another Member stated that GPs wanting to work with CAMHS sometimes found this difficult and often the issue could be complicated by the educational and behavioural circumstances of the child or young person involved.

- 5.6 A Member asked whether the Board could be provided with a draft of the Written Statement of Action if the inspection so required this. The Chairman added that it was important that that the Board receive any feedback from the inspection at the earliest opportunity.
- 5.7 In reply to issues raised by Members, Victor Roman advised that the Board would receive a draft of a Written Statement of Action if this was required and the Board would also be involved in the co-production of it. He stated that the Board would receive feedback about the inspection regardless of the outcome in any case and he acknowledged the Chairman's request to provide this at the earliest opportunity.
- 5.8 Alison Markwell (Designated Clinical Officer for SEND, NHS Central London, West London, Hammersmith and Fulham, Houslow and Ealing CCGs) advised that the SEND inspections were taking place over a 5 year period and the expected standards were rising. Requests for Written Statements of Action were becoming increasingly common and so therefore there was a greater likelihood that this local area would also be requested to do so. Alison Markwell emphasised the importance of ensuring that all partner organisations were 'on message' and to demonstrate services being co-designed and co-produced. She advised that work was taking place with parent carer forums in respect of young people, and also Re-Think. Schools were also well placed to address mental health issues, with some having mental health champions and there was also online access to counselling and it was important to demonstrate what was available at the local level during the inspection. Alison Markwell acknowledged the need for early intervention in respect of mental health amongst children and young people. The Board noted that the inspection could fall anytime between April and September, although not during school holidays.
- 5.9 The Chairman concurred on the importance of focusing on mental health in primary schools. The Chairman also requested that information on the source of funding that the Central and North West London NHS Foundation was receiving to undertake early preventative work in primary schools in the area be provided.



## **6 BETTER CARE FUND PROGRAMME 2017-19: PROGRESS MONITORING REPORT**

- 6.1 Dylan Champion (Head of Health Partnerships) presented the report and advised that good progress was being made in implementing the Better Care Fund (BCF) Programme for 2017-19. Coherent plans were also in place for 2018-19 and 2019-20. A review had been undertaken to ensure that pooled budgets under the Section 75 agreements would result in improved value for money and efficiency. Dylan Champion added that new arrangements for a seven day a week Hospital Social Work Team had been in place since January 2017 at no additional cost.
- 6.2 During discussions, Members asked for more information about the source of funding and could the Board monitor the implementation of the BCF Programme for 2017-19.
- 6.3 In reply, Dylan Champion advised that the core funding for the BCF came from the Department of Health with a contribution in the region of £28 million being provided. A further £9 million came from the Department of Communities and Local Government. In respect of the tri-borough Section 75 agreements, Dylan Champion advised that each agreement was sovereign to the individual borough and details of these could be provided to the Board.
- 6.4 Bernie Flaherty (Bi-borough Director of Adult Social Care) advised that now that the BCF Programme 2017-19 had been agreed, the Board's role was to generally monitor it, although Members could request to look at particular areas of the programme. The Chairman added that the Adults and Health Policy and Scrutiny Committee role included monitoring areas such as the BCF.
- 6.5 The Board noted the progress on the BCF Programme 2017-19 to date.

## **7 SUICIDE PREVENTION ACTION PLAN 2018-2021**

- 7.1 John Forde (Deputy Director of Public Health) presented the report and advised that he had received some comments from Members since the draft Suicide Action Plan 2018-2021 had been presented at the previous meeting. Approval of the finalised Action Plan was now sought and John Forde added that the support of the Board and partner agencies was sought in implementing it.
- 7.2 A Member commented that it was right that suicide prevention was a high priority, particularly in view of the high suicide rates amongst men in Westminster. He emphasised that there should also be a focus on prevention in schools and early years.
- 7.3 The Chairman advised that Councillor Karen Scarborough (Deputy Cabinet Member for Children, Families and Young People) had commented favourably on the Action Plan. She added that she had received a request to provide funding for a London wide social media campaign to tackle suicide and asked for further information on this campaign from officers.

- 7.4 In reply to queries from Members, Elizabeth Dunsford (Senior Strategic Relationships and Outcomes Officer) acknowledged that suicide prevention was a high priority, especially in view of the comparatively high number of suicides in Westminster. She added that useful data had been received from the British Transport Police in respect of suicides and in particular where this involved men in Central London.
- 7.5 John Forde agreed to provide the Chairman with further information on a London wide social media campaign addressing suicide prevention.
- 7.6 The Board endorsed the action plan and agreed to monitor its progress on an annual basis.

## **8 PHARMACEUTICAL NEEDS ASSESSMENT 2018-21**

- 8.1 Colin Brodie (Public Health Manager) presented the report that sought approval for the Pharmaceutical Needs Assessment (PNA) 2018-21. The draft PNA had been presented to the Board on 16 November 2017 and had subsequently been subject to a consultation from 1 December 2017 to 2 February 2018. Colin Brodie advised that the updated PNA had been duly informed by both the Board and consultation responses and that the PNA was statutorily required to be published by 1 April.
- 8.2 During discussions, Dr Nami Katz (NHS West London Clinical Commissioning Group) welcomed that some GPs also had pharmacies within the same site and some pharmacies undertook medication reviews where patients were on 4 or more medications. She agreed to pass on details to Dr Neville Pursell (NHS Central London Clinical Commissioning Group) and Colin Brodie on this scheme. She added that some pharmacies were not open for as long as hours as GPs were.
- 8.3 Members concurred that the PNA highlight the desirability of pharmacies offering uniformity in terms of prescription length and of the need for pharmacies to ensure that they provide good quality care. The Local Pharmaceutical Committee should also note the Board's concerns on this. Members asked whether the performance of pharmacies in respect of needle exchanges was satisfactory and being offered at the right locations or whether there was a need to improve this service. In respect of the Stop Smoking Service, the Chairman added that the PNA should mention that Westminster was the leading performer amongst London boroughs in getting people to stop smoking.
- 8.4 In reply to the points raised by the Board, Colin Brodie acknowledged the requests made by Members and added that NHS England could also monitor the quality of service provided by NHS England. He advised that Westminster was well provided with pharmacies offering needle exchange services and access levels were high. However, he would look at whether there was scope to do more and agreed to Members' request that this service be promoted more in the PNA.

8.5 The Board approved the PNA 2018-2021, subject to the additional comments made above.

**9 ANY OTHER BUSINESS**

9.1 Councillor Barrie Taylor stated that he was a member of the Health and Wellbeing Centres Task Group and he suggested that the final report be circulated to the Board and this was agreed by Members. Members also agreed to the Chairman's suggestion that the Board workshop take place on the date of the next scheduled meeting on 24 May.

9.2 On behalf of the Board, the Chairman thanked Councillor Barrie Taylor, who was stepping down from being a councillor, and John Forde and Dylan Champion, who were leaving the Council, for their work and contributions to the Board.

The Meeting ended at 6.26 pm.

**CHAIRMAN:** \_\_\_\_\_

**DATE** \_\_\_\_\_

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# WESTMINSTER HEALTH & WELLBEING BOARD

## Actions Arising

### Meeting on Tuesday 20<sup>th</sup> March 2018

Action	Lead Member(s) And Officer(s)	Comments
<b>Minutes and Actions Arising</b>		
Board to receive an annual report from the Care Quality Commission on its overall work.	Chris Neill / Bernie Flaherty / Dylan Champion	
<b>Local Area Special Educational Needs and Disability Brief</b>		
Chairman to receive information on source of funding received by Central and North West London NHS Foundation Trust on preventative work on mental health in primary schools.	Victor Roman / Alison Markwell	
<b>Suicide Prevention Action Plan 2018-2021</b>		
Chairman to receive further information on London wide social media campaign on suicide prevention.	John Forde	
<b>Any Other Business</b>		
Health and Wellbeing Centres Task Group report to be circulated to the Board.	Toby Howes	Completed.

### Meeting on Thursday 18<sup>th</sup> January 2018

Action	Lead Member(s) And Officer(s)	Comments
<b>Verbal Update on the work of the Safer Westminster Partnership</b>		
Mick Smith to discuss emergency care and ambulance callouts with NHS Central London Clinical Commissioning Group.	Mick Smith / Chris Neill	
<b>Suicide Prevention Strategy Refresh</b>		
Chris Neill to approach Like Minded to discuss linking up of their work with the Suicide Prevention Strategy.	Chris Neill	

### Meeting on Thursday 16<sup>th</sup> November 2017

Action	Lead Member(s) And Officer(s)	Comments
<b>Chairman's Verbal Update</b>		
Chairman to update Board on meeting she had with NHS Property representatives at next Board meeting.	Chairman	Completed.

**Pharmaceutical Needs Assessment**

Mike Robinson to contact NHS England to see if inviting pharmacy representatives to a future Board where the Pharmaceutical Needs Assessment is an item on the agenda is appropriate.

Mike Robinson

**Meeting on Thursday 14<sup>th</sup> September 2017**

Action	Lead Member(s) And Officer(s)	Comments
<b>Sustainability and Transformation Plan</b>		
Presentation on Sustainability and Transformation Plan to be circulated to the Community Safety Partnership.	Jane Wheeler / Chris Neill	
<b>Draft Annual Report of the Director of Public Health 2016-17</b>		
Members to make any further comments and suggestions about the draft annual report to Mike Robinson prior to the next Board meeting.	All Board Members / Mike Robinson	Completed.

**Meeting on Thursday 13<sup>th</sup> July 2017**

Action	Lead Member(s) And Officer(s)	Comments
<b>Update on Development of Better Care Fund Plan 2017-19</b>		
Better Care Fund Plan for 2017-19 to be circulated to Members for further comments and final approval to be delegated to Councillor Heather Acton and Dr Neville Pursell before the 11 September deadline.	Councillor Heather Acton / Dr Neville Pursell / Dylan Champion	Completed.
<b>Work Programme</b>		
Clarification to be provided on whether the meeting scheduled for 22 March 2018 needs to be moved forward.	Councillor Heather Acton / Dylan Champion	Completed.

**Meeting on Thursday 25<sup>th</sup> May 2017**

Action	Lead Member(s) And Officer(s)	Comments
<b>Delivering the Health and Wellbeing Strategy for Westminster</b>		
Information dashboard being developed by North West London Clinical Commissioning Groups' Strategy Transformation Team to be circulated at next meeting.	Harley Collins (Health and	Completed.

	Wellbeing Manager)	
Healthwatch to circulate research undertaken on behalf of the North West London Sustainability Transformation Plan that identified gaps in the Community Independence Service to Members.	Healthwatch	Completed.
Specific priorities and projects within the Strategy to be updated to incorporate suggestions made by Members.	Dylan Champion	To be provided at a future meeting.
<b>Work Programme</b>		
Updated work programme to be circulated to Members.	Dylan Champion	To be provided at a future meeting.
Primary Care Strategy to be circulated to Members.	Chris Neill (NHS Central London Clinical Commissioning Group)	

#### Meeting on Thursday 2<sup>nd</sup> February 2017

Action	Lead Member(s) And Officer(s)	Comments
<b>Health and Wellbeing Strategy for Westminster 2017 – 2022 Implementation</b>		
A joint implementation paper setting out a clear governance structure and providing details of actions being taken by NHS Central London and NHS West London Clinical Commissioning Groups to help deliver the implementation plan to be provided at next meeting.	Ezra Wallace, Chris Neill (NHS Central London Clinical Commissioning Group) and Louise Proctor (NHS West London Clinical Commissioning Group)	Completed.
<b>Pharmaceutical Needs Assessment – Introduction</b>		
Report on implications for funding for community pharmacies being reduced for 2016/17 and 2017/18 to be provided at a future meeting.	Colin Brodie	To be provided at a future meeting.

#### Extraordinary Meeting on Tuesday 13<sup>th</sup> December 2016

Action	Lead Member(s) And Officer(s)	Comments
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**NHS Central London and NHS West London Clinical Commissioning Groups' Commissioning Plans**

Members to provide any further comments on the Commissioning Plans by 20 December.	All Board Members	Completed.
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**Meeting on Thursday 17<sup>th</sup> November 2016**

Action	Lead Member(s) And Officer(s)	Comments
<b>Update on the North West London Sustainability Transformation Plan and Westminster's Joint Health and Wellbeing Strategy</b>		
Board's comments in respect of the North West London Sustainability Transformation Plan to be fed back to the NHS Central and NHS North West London Clinical Commissioning Groups.	Chris Neill (NHS Central London Clinical Commissioning Group)	Completed.
<b>Work Programme</b>		
Board to receive first report on the next Pharmaceutical Needs Assessment at next meeting.	Mike Robinson / Colin Brodie	Completed.

**Meeting on Thursday 15<sup>th</sup> September 2016**

Action	Lead Member(s) And Officer(s)	Comments
<b>Draft Westminster Health and Wellbeing Strategy Refresh</b>		
Final strategy to be put to the Board at the next meeting.	Meenara Islam	Completed.
<b>Housing Support and Care Joint Strategic Needs Assessment</b>		
Board to look at the Housing Support and Care Joint Strategic Needs Assessment in more detail and to support the recommendations, subject to any concerns raised by Members in the next two weeks.	All Board Members / Anna Waterman	Completed.

**Meeting on Thursday 14<sup>th</sup> July 2016**

Action	Lead Member(s) And Officer(s)	Comments
<b>Draft Westminster Health and Wellbeing Strategy Refresh</b>		
Meenara Islam to circulate the dates that the consultation events and meetings are taking place to Members.	Meenara Islam	Completed.



<b>Tackling Childhood Obesity Together</b>		
Progress on the programme to be reported back to the Board in a year's time.	Eva Hrobonova	
<b>Health and Wellbeing Hubs</b>		
Details of the children's workstream to be reported to the Board at the next meeting.	Melissa Caslake	Completed.

#### Meeting on Thursday 26<sup>th</sup> May 2016

Action	Lead Member(s) And Officer(s)	Comments
<b>Draft Westminster Health and Wellbeing Strategy Refresh</b>		
Members to provide any further input on the strategy before it goes to consultation at the beginning of July.	All Board Members	Completed

#### Meeting on Thursday 17<sup>th</sup> March 2016

Action	Lead Member(s) And Officer(s)	Comments
<b>Westminster Health and Wellbeing Strategy Refresh Update</b>		
Members requested to attend Health and Wellbeing Board workshop on 5 April.	All Board Members	Completed.
Meenara Islam to circulate details of proposals discussed at an engagement plan meeting between Council and Clinical Commissioning Group colleagues.	Meenara Islam	Completed.
<b>NHS Central and NHS West London Clinical Commissioning Group Intentions</b>		
Clinical Commissioning Groups to consider how future reports are to be presented with a view to producing reports more similar in format and more user friendly.	Clinical Commissioning Groups	On-going.

#### Meeting on Thursday 21<sup>st</sup> January 2016

Action	Lead Member(s) And Officer(s)	Comments
<b>Commissioning Intentions: (A) NHS Central London Clinical Commissioning Group; (B) NHS West London Clinical Commissioning Group</b>		
Update on the Clinical Commissioning Groups' intentions to be reported at the next Board meeting.	Clinical Commissioning Groups	Completed.

<b>Westminster Health and Wellbeing Strategy Refresh</b>		
Draft proposals for the strategy refresh to be considered at the next Board meeting	Adult Social Care, Clinical Commissioning Groups and Policy, Performance and Communication	Completed.

### Meeting on Thursday 19<sup>th</sup> November 2015

Action	Lead Member(s) And Officer(s)	Comments
<b>Westminster Health and Wellbeing Hubs Programme Update</b>		
Update on the Programme to be reported at the next Board meeting.	Adult Social Care	Completed.
<b>Like Minded – North West London Mental Health and Wellbeing Strategy – Case for Change</b>		
Board to receive report on Future In Mind programme to include details of how it will impact upon Westminster and how the Board can feed into the programme to provide more effective delivery of mental health services.	Children's Services	Completed.
Board to receive report on young people's services, including how they all link together in the context of changes to services.	Children's Services	Completed.

### Meeting on Thursday 1<sup>st</sup> October 2015

Action	Lead Member(s) And Officer(s)	Comments
<b>Central London Clinical Commissioning Group – Business Plan 2016/17</b>		
West London Clinical Commissioning Group to circulate their Business Plan 2016/17 to the Board.	West London Clinical Commissioning Group	Completed.
<b>Westminster Health and Wellbeing Hubs Programme Update</b>		
Board to nominate volunteers to be involved in the Programme and to be on the Working Group.	Meenara Islam	Completed.
Update on the Programme to be reported at the next Board meeting.	Adult Social Care	Completed.

**Dementia Joint Strategic Needs Assessment – Commissioning Intentions and Sign Off**

Board to receive and update at the first Board meeting in 2016.	Public Health	Completed.
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**Meeting on Thursday 9<sup>th</sup> July 2015**

Action	Lead Member(s) And Officer(s)	Comments
<b>Five Year Forward View and the Role of NHS England in the Local Health and Care System</b>		
That a document be prepared comparing NHS England's documents with the Clinical Commissioning Groups to demonstrate how they tie in together.	Clinical Commissioning Groups/NHS England	Completed.
Board to receive regular updates on the work of NHS England and to see how the Board can support this work.	NHS England	To be considered at future meetings.
<b>Westminster Housing Strategy</b>		
Housing Strategy to be brought to a future meeting for the Board to feed back its recommendations.	Spatial and Environmental Planning	Completed.
<b>Update on Preparations for the Transfer of Public Health Responsibilities for 0-5 Years</b>		
Board to receive an update in 2016.	Public Health	Completed.

**Meeting on Thursday 21<sup>st</sup> May 2015**

Action	Lead Member(s) And Officer(s)	Comments
<b>North West London Mental Health and Wellbeing Strategic Plan</b>		
That a briefing paper be prepared outlining how the different parts of the mental health services will work and how various partners can feed into the process.	NHS North West London	Completed.
Adult Social Care representative to be appointed onto the Transformation Board.	NHS North West London Adult Social Care	Completed.
<b>Children and Young People's Mental Health</b>		
A vision statement be produced and brought to a future Board meeting setting out the work to be done in considering mental health services for 16 to 25 year	Children's Services	Completed.

olds, the pathways in accessing services and the flexibility in both the setting and the type of mental health care provided, whilst embracing a multidisciplinary approach.		
<b>The role of pharmacies in Communities and Prevention</b>		
Public Health Team and Healthwatch Westminster to liaise and exchange information in their respective studies on pharmacies, including liaising with the Local Pharmaceutical Committee and the Royal Pharmaceutical Society.	Public Health Healthwatch Westminster	Completed.
<b>Whole Systems Integrated Care</b>		
That the Board be provided with updates on progress for Whole Systems Integrated Care, with the first update being provided in six months' time.	NHS North West London	Completed.
<b>Joint Strategic Needs Assessment</b>		
Consideration be given to ensure JSNAs are more line with the Board's priorities.	Public Health	Completed.
The Board to be informed more frequently on any new JSNA requests put forward for consideration.	Public Health	On-going.
<b>Better Care Fund</b>		
An update including details of performance and spending be provided in six months' time.		Completed.
<b>Primary Care Co-Commissioning</b>		
Further consideration of representation, including a local authority liaison, to be undertaken in respect of primary care co-commissioning.	Health and Wellbeing Board	In progress
<b>Work Programme</b>		
Report to be circulated on progress on the Primary Care Project for comments.	Holly Manktelow Health and Wellbeing Board	Completed.
The Board to nominate a sponsor to oversee progress on the Primary Care Project in between Board meetings.	Health and Wellbeing Board	To be confirmed.
NHS England to prepare a paper describing how they see their role on the Board and to respond to Members' questions at the next Board meeting.	NHS England	Completed.

Action	Lead Member(s) And Officer(s)	Comments
<b>Pharmaceutical Needs Assessment</b>		
Terms of reference for a separate wider review of the role of pharmacies in health provision, and within integrated whole systems working and the wider health landscape in Westminster, to be referred to the Board for discussion and approval.	Adult Social Care	Completed

### Meeting on Thursday 22<sup>nd</sup> January 2015

Action	Lead Member(s) And Officer(s)	Comments
<b>Better Care Fund Plan</b>		
Further updates on implementation of the Care Act to be a standing item on future agendas.	Adult Social Care	Completed.
<b>Child Poverty</b>		
Work to be commissioned to establish whether and how all Council and partner services contributed to alleviating child poverty and income deprivation locally, through their existing plans and strategies – to identify how children and families living in poverty were targeted for services in key plans and commissioning decisions, and to also enable effective identification of gaps in provision.	Children's Services	In progress.
To identify an appropriate service sponsor for allocation to each of the six priority areas, in order to consolidate existing and future actions that would contribute to achieving objectives.	Children's Services	In progress.
<b>Local Safeguarding Children Board Protocol</b>		
Protocol to be revised to avoid duplication and to be clear on the different and separate roles of the Health & Wellbeing Board and the Scrutiny function.	Local Safeguarding Children Board	Completed.
<b>Primary Care Commissioning</b>		
A further update on progress in Primary Care Co-Commissioning to be given at the meeting in March 2015.	Clinical Commissioning Groups.  NHS England	Completed.

### Meeting on Thursday 20<sup>th</sup> November 2014

Action	Lead Member(s) And Officer(s)	Comments
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<b>Primary Care Commissioning</b>		
The possible scope and effectiveness of establishing a Task & Finish Group on the commissioning of Primary Care to be discussed with Westminster's CCGs and NHS England, with the outcome be reported to the Health & Wellbeing Board.	Clinical Commissioning Groups  NHS England	Completed
<b>Work Programme</b>		
A mapping session to be arranged to look at strategic planning and identify future agenda issues.	Health & Wellbeing Board	Completed.

### Meeting on Thursday 18<sup>th</sup> September 2014

<b>Action</b>	<b>Lead Member(s) And Officer(s)</b>	<b>Comments</b>
<b>Better Care Fund Plan 2014-16 Revised Submission</b>		
That the final version of the revised submission be circulated to members of the Westminster Health & Wellbeing Board, with sign-off being delegated to the Chairman and Vice-Chairman, subject to any comments that may be received.	Director of Public Health.	Completed.
<b>Primary Care Commissioning</b>		
The Commissioning proposals be taken forward at the next meeting of the Westminster Health & Wellbeing Board in November	NHS England	Completed.
Details be provided of the number of GPs in relation to the population across Westminster, together with the number of people registered with those GPs; those who are from out of borough; GP premises which are known to be under pressure; and where out of hours capacity is situated.	NHS England	Completed.
<b>Measles, Mumps and Rubella (MMR) Vaccination In Westminster</b>		
That a further report setting out a strategy for how uptake for all immunisations could be improved, and which provides Ward Level data together with details of the number of patients who have had measles, be brought to a future meeting of the Westminster Health & Wellbeing Board in January 2015.	NHS England Public Health.	Completed.

### Meeting on Thursday 19<sup>th</sup> June 2014

<b>Action</b>	<b>Lead Member(s) And Officer(s)</b>	<b>Comments</b>
<b>Whole Systems</b>		

Business cases for the Whole Systems proposals to be submitted to the Health & Wellbeing Board in the autumn.	Clinical Commissioning Groups.	Completed.
<b>Childhood Obesity</b>		
A further report to be submitted to a future meeting of the Westminster Health & Wellbeing Board by the local authority and health partners, providing an update on progress in the processes and engagement for preventing childhood obesity.	Director of Public Health.	Completed.
<b>The Health &amp; Wellbeing Strategy</b>		
A further update on progress to be submitted to the Westminster Health & Wellbeing Board in six months.	Priority Leads.	Completed.
<b>NHS Health Checks Update and Improvement Plan</b>		
Westminster's Clinical Commissioning Groups to work with GPs to identify ways of improving the effectiveness of Health Checks, with a further report on progress being submitted to a future meeting.	Clinical Commissioning Groups	Completed.
<b>Joint Strategic Needs Assessment Work Programme</b>		
The implications of language creating a barrier to successful health outcomes to be considered as a further JSNA application.  <i>Note: Recommendations to be put forward in next year's programme.</i>	Public Health Services  Senior Policy & Strategy Officer.	Completed.

### Meeting on Thursday 26<sup>th</sup> April 2014

Action	Lead Member(s) And Officer(s)	Comments
<b>Westminster Housing Strategy</b>		
The consultation draft Westminster Housing Strategy to be submitted to the Health & Wellbeing Board for consideration.	Strategic Director of Housing	Completed.
<b>Child Poverty Joint Strategic Needs Assessment Deep Dive</b>		
A revised and expanded draft recommendation report to be brought back to the Health & Wellbeing Board in September.	Strategic Director of Housing Director of Public Health.	Completed.
<b>Tri-borough Joint Health and Social Care Dementia Strategy</b>		
Comments made by Board Members on the review and initial proposals to be taken into account when drawing up the new Dementia Strategy.	Matthew Bazeley Janice Horsman Paula Arnell	Completed.
<b>Whole Systems</b>		

A further update on progress to be brought to the Health & Wellbeing Board in June.	Clinical Commissioning Groups	Completed.
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## Westminster Health & Wellbeing Board

<b>Date:</b>	24 <sup>th</sup> May 2018
<b>Classification:</b>	General Release
<b>Title:</b>	Co-ordinated care? Patients' and their carers' experiences of living with long-term health conditions in Westminster 2018.
<b>Report of:</b>	Healthwatch Central West London
<b>Report Author and Contact Details:</b>	Carena Rogers, Programme Manager Healthwatch Central West London; carena.rogers@healthwatchcentralwestlondon.org

### **1. Executive Summary**

- 1.1 This draft report contains findings from our engagement with people living with long term health conditions, or carers of people with long term health conditions living in Westminster.
- 1.2 This report sets out the experiences of people with long term health conditions and their carers of accessing support to manage their health conditions through their GP practices. It also sets out their aspirations for what support should be available in the future.

### **2. Key Matters for the Board**

- 2.1 We ask the Health and Wellbeing Board to acknowledge the experiences that people with long term health conditions have had of receiving support through their GP practice.
- 2.2 We also ask the Health and Wellbeing Board to comment on the report before we make the report generally available to members of the public.

### **3. Background**

- 3.1 Healthwatch Central West London held a series of public meetings at which we asked local people about their experiences of health and care services in their area. People told us they were unsure of how to access additional support for people

living with long-term health conditions. They were concerned that friends and neighbours were slipping through the net and not getting the support they needed.

### **What did we do?**

- 3.2 In April 2017 we set up a Project Group made up of members from the Older Adults Group at the Advocacy Project to provide advice and direction. As local primary care services are undergoing reconfiguration in Westminster, with further changes yet to be implemented, the Project Group agreed that we should find out more about people's experiences of support offered through GP practices to help them manage their long-term health conditions, to ensure that it is meeting people's health and support needs.
- 3.3 During June to August 2017 we surveyed people with long term health conditions and their carers living in Westminster. We held four focus groups in August and September 2017, including one for carers. In September and November 2017, further telephone interviews were held with people with long term health conditions. In total, we spoke to 85 people. The people we spoke to had a range of long term health conditions including Diabetes, respiratory conditions, Multiple Sclerosis, and Muscle Skeletal Disorders amongst others.

### **Report conclusions**

- 3.4 This report aimed to provide a picture of the current experiences of people living with long-term health conditions and their carers in Westminster. The main questions explored are:
- What type of support patients received through their GP practice to help them manage their long-term health condition; and
  - How easy it was for patients to get the help they need for their long-term health condition through their GP practice.
- 3.5 We heard mixed experiences of the type of support available through GP practices to support people to manage their long-term health conditions. It was very apparent in focus group discussions that the support on offer was varied depending on which GP practice participants were registered at.
- 3.6 We heard that some patients and carers have good experiences of receiving help to manage their, or the person's that they care for, long-term health condition. The relationship built up with the GP and having a personalised response to their health or care needs seemed to be key to this.
- 3.7 However, two-thirds of our survey respondents said that they found it hard to get the help they needed to manage their long-term health from their GP practice. They, and the focus group participants highlighted a range of difficulties that they encountered:

### **Clear patient pathway**

- 3.8 Patients and carers would like services to work better together. Patients and carers manage their different appointments themselves and medical professionals are not always aware of other clinicians involved with the healthcare of the patient.
- 3.9 Patients and carers also wanted medical professionals to be better at communicating with each other: to share information about individual patients so that support was better co-ordinated; to inform each other what their role was; and to be clear what the service they worked for could offer.
- 3.10 Patients and carers would like more information about health and wellbeing support available from community and voluntary organisations. This support could help them better manage their, or the person's they care for, health conditions. It could also help them build relationships with others in their local community with whom they could share information, offer support and reduce their isolation.

### **Patient Participation Groups**

- 3.11 We heard clearly in the focus groups that both patients and carers would like to be more involved in deciding and evaluating what help was available for people with long-term health conditions through the GP practice. People wanted to be asked their opinions about what support was on offer and what could be done differently.
- 3.12 When informed about Patient Participation Groups, many focus group participants felt that these would be good fora for them to feed in information about their experiences of the support available at their GP practice and to express an opinion on what could be changed to improve provision.

### **Support for mental health conditions and wellbeing**

- 3.13 Both patients and carers struggled to get help for their mental health and wellbeing when it was needed and at times got sent from one service to another, with the GP unable to meet their needs.

### **Carers**

- 3.14 The carers we spoke to were caring for relatives and friends with a range of health needs. The people they were caring for tended to need a high level of support and were accessing a number of different health services. Carers felt that they were expected to co-ordinate a lot of the care themselves and did not feel that they had enough information of support to do this.

- 3.15 None of the carers we spoke to had had their own needs assessed and they reported that they would like to have someone who was looking after their own health and wellbeing.

### **Attitude of staff working in primary care settings**

- 3.16 The negative and unhelpful attitudes that both patients and carers experienced from staff working in a range of primary care settings, including GP practices adds to the difficulties they face in managing their, or the person's they care for, long-term health condition.

### **Report Recommendations:**

- 3.17 **Recommendation 1:** GP practices give patients and carers with long-term health conditions clear information about the support they will receive to help them manage their health condition.

- 3.18 This should include information on:

- Who is eligible to receive additional support to help them manage their long-term health conditions
- What support can be offered through the GP practice
- How to ask for extra support to manage a long-term health condition from their GP practice
- How their GP will consult with them to help them to identify what help they need and what support is available.
- How the GP and other health and care professionals will ensure a personalised approach is taken so that the patient is in charge of the care they receive to manage their long-term health condition
- How the GP practice will co-ordinate their care with other healthcare professionals and how this will be communicated to the patient

- 3.19 Once a patient is receiving additional support, their care plan should clearly state:
- Who their named contact is that they can go to for further information and advice. Any changes to this should be clearly communicated to the patient
  - Details on how to contact their named healthcare professional
  - Information about their long-term health condition and self-care advice
  - What health and care services they are receiving and how to contact them
  - How to access other local community support and resources

- 3.20 **Recommendation 2:** GP practices are supported by the CCG to develop PPGs in their practice and to demonstrate how they have listened to patients and carers, and made changes based on their experiences.

- 3.21 **Recommendation 3:** Recruitment and engagement of new and existing PPG members should target patients with long-term health conditions and their carers.

- 3.22 **Recommendation 4:** PPG members should be given opportunities to share their experiences at a wider CCG level through engagement in the new Primary Care Homes as they are formed so that patient experience is used to shape service provision, communication and improvements.
- 3.23 **Recommendation 5:** Patients with long-term health conditions and their carers are regularly asked about their mental wellbeing and are referred to mental health support where needed and signposted to community and voluntary organisations that offer services to support mental wellbeing.
- 3.24 **Recommendation 6:** All carers for people with long-term health conditions should be offered a named professional based in the GP practice, with clear information on how they can be contacted, focused on supporting their own health and mental wellbeing.
- 3.25 **Recommendation 7:** Staff across the range of provision in GP practices should be regularly reminded of their responsibilities under guidance from NHS England on how to support long-term conditions to ensure that people with long-term health condition have access to home visits, medication reviews, etc. to support a good quality of life.

#### **4. Options / Considerations**

4.1 N/A

#### **5. Legal Implications**

5.1 N/A

#### **6. Financial Implications**

6.1 N/A

**If you have any queries about this Report or wish to inspect any of the Background Papers please contact:**

**Carena Rogers; Programme Manager, Healthwatch Central West London**

**Email: [carena.rogers@healthwatchcentralwestlondon.org](mailto:carena.rogers@healthwatchcentralwestlondon.org)**

**Telephone: 020 8968 7049**

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# Healthwatch Central West London

## Co-ordinated care? Patients' and their carers' experiences of living with long-term health conditions in Westminster



# Contents

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1. Introduction .....	2
2. Methodology .....	3
3. Background information.....	5
4. Primary Care Support for people living with long-term health conditions.....	11
5. Conclusion and Recommendations .....	24
6. What happens next?.....	28
7. Appendix .....	28
Survey: When it comes to managing your health condition, do you get the support that you need from your GP practice?.....	28
7. Contact us .....	33





# 1. Introduction

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A key aspect of Healthwatch Central West London's (Healthwatch CWL) work is to provide information to the public about healthcare and changes in local provision. We also listen to people's experiences of accessing healthcare.

In 2016 - 2017 Healthwatch Central West London (Healthwatch CWL) held a series of public meetings at which we asked local people about their experiences of health and care services in their area. People told us that there was little support to help them stay well and manage their long-term health conditions. Others reported that they were unsure of how to access additional support for people living with long-term health conditions. They were concerned that friends and neighbours were slipping through the net and not getting the support they needed.

Long-term health conditions include conditions such as: Diabetes, lung and heart conditions, Multiple Sclerosis, and Muscle Skeletal Disorders, amongst others.

To find out more about what support people were receiving and what support should be available for people with long term health conditions Healthwatch CWL teamed up with the Older Adults Group at the Advocacy Project. We set up a small steering group of four older adults who advised and directed the work. We met every two weeks from April to September 2017.


The Project Group agreed that there is a need to monitor the support available to people with long term health conditions offered through GP practices to ensure that it is meeting people's health and support needs; and to ensure that people who use the service can influence how the service is evaluated and improved.

With changes to primary care still to come there is a need for Healthwatch CWL to closely monitor whether these changes are benefiting local people. We set out to discover more about people's current experiences of support offered through GP practices to help them manage their long-term health conditions. We created a survey and held a series of focus groups in which we talked to patients and carers about their experiences of using primary care to help them manage their, or the person they care for, long-term health condition.

This report sets out the survey responses and focus group discussions in the context of the changing environment in provision of primary care across the borough. It aims to build a comprehensive picture of patients' and carers' views and experiences of accessing support through primary care for long-term health conditions. This will enable key decision makers, commissioners and providers to better understand the

types of provision that local people need and prefer to help them stay well and manage their long-term health conditions.

The main questions explored are:

- 
- What type of support patients received through their GP practice to help them manage their long-term health condition; and
  - How easy was it for patients to get the help they need for their long-term health condition through their GP practice.

## 2. Methodology

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### What did we do?

To hear more about people's experiences of living with a long-term condition and how their GPs supported them, we designed a survey for people with long term health conditions or their carers, which was live through June to September 2017. We promoted this on our website and through partner agencies. In total, we received 45 responses.

We invited three Care Navigators from the Care Co-ordination Service provided by Central London Healthcare to attend our Project Group meeting and tell us more about the service that they offer.

We held four focus groups in August and September 2017, which included one for carers. Participants were recruited by working with other organisations such as Open Age Westminster; Carers Network; and Breathe Easy Westminster. We spoke to 35 people in the focus groups.

Further telephone interviews were held in September - November 2017 with people with long-term health conditions or their carers living in Westminster who were identified through the survey.

The survey focused on:

- What type of support patients received through their GP practice to help them manage their long-term health condition; and
- How easy it was for patients to get the help they need for their long-term health condition through their GP practice

In the focus groups we explored this in more depth and also asked participants what could be changed so that their health needs were better met

### Who did we speak to?



This report includes the views of 85 people either living with long-term health conditions or caring for someone who has a long-term health condition in Westminster. The people we spoke to each had a range of long term health conditions including Diabetes, respiratory conditions, Multiple Sclerosis, and Muscle Skeletal Disorders, amongst others. The majority (86%) of people we spoke to had had their long-term health condition for over three years

The ages of the people who engaged with us ranged from one person in the 18-25 age group to those above 80 years. Over two-thirds of people we spoke to were aged 60 years or older (77%); with just under half (49%) aged 70 years or older.

Half of the respondents to the survey stated that they were carers (50%). In the focus groups about a fifth (22%) said that they were carers. We carried out one focus group specifically for carers; this was attended by eight people.

Not all respondents to the survey informed us of which GP practice they were registered at but the 25 that did, were registered at 16 of the GP practices in Central London and two in Queen's Park and Paddington area. There was a good spread across the borough, although this was slightly weighted towards the north.



## 3. *Background information*

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Healthwatch CWL held a series of focus groups and surveys in Westminster during June and July 2016. These highlighted that local people were unsure of how to access support for people who were struggling with their long-term health conditions. People were concerned that friends and neighbours were slipping through the net and not getting the support that they needed.

At the same time care coordination services in GP practices in Westminster were changing. A new Care Coordination Service (CCS) was launched in July 2016 by Central London Healthcare (CLH). Initially this was to be a two year offer with a social prescription element being piloted in selected GP surgeries in 'Wave 1 Villages'. The social prescription offer was subsequently rolled out to most GP practices in Central London CCG.

## Social prescription

“Social prescribing enables GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services. Social prescribing seeks to address people’s needs in a holistic way. It also aims to support individuals to take greater control of their own health.”

“Social prescribing schemes can involve a variety of activities which are typically provided by voluntary and community sector organisations. Examples include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of sports.”

The King’s Fund<sup>1</sup>

## Changes to local health and care systems

The Five Years Forward View<sup>2</sup>, published by NHS England and its partners sets out the vision for the future of the NHS. It notes that ‘long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected “episodes” of care.’

Both Westminster City Council and Central London CCG are working to create a local care system that is integrated across health, social care and voluntary sector partners to support people’s health and wellbeing outcomes. The North West London Sustainability and Transformation Plan (STP) for the eight CCGs in the STP footprint set out that this can best be achieved through an accountable care system that incorporates an integrated system across health and care, supported by joined up funding and aligned outcomes for local people. This aim is being supported at a local Westminster borough level by the Westminster Health and Wellbeing Strategy 2017 - 2022 and Central London CCG’s Primary Care Strategy.

The projected number of people living in Westminster with a range of long-term health conditions is expected to rise over the next ten to 15 years.<sup>3</sup> The Westminster Health and Wellbeing Strategy 2017 - 2022 has as one of its priorities a commitment to reduce the risk factors for, and improve the management of, long-term conditions. Likewise, CLCCG also has a commitment to better care for people with long-term health conditions in its Primary Care Strategy. These are set out below.

## Westminster Health and Wellbeing Strategy 2017 - 2022

<sup>1</sup> <https://www.kingsfund.org.uk/publications/social-prescribing>

<sup>2</sup> <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/our-work-on-long-term-conditions/>

<sup>3</sup> <http://www.centrlondonccg.nhs.uk/media/47656/Evidence-Base-FINAL.pdf>

The Westminster Health and Wellbeing Strategy includes a specific priority aimed at improving support for people living with a long-term health condition in Westminster (Box 1). This includes a commitment to consider the experiences and needs of people with long-term conditions and working with them and their carers to develop services. There are a range of outcomes underpinning this priority, including:

- *'I have a named point of contact who understands me and my condition(s).*
- *I feel that the health and care services and staff I engage with understand my specific needs and listen to me', and*
- *'I am supported to remain independent and stay living in my own home'.*

### **Box 1: Westminster Health and Wellbeing Strategy 2017 - 2022**

#### **Priority 2: Reducing the risk factors for, and improving the management of, long-term conditions, such as dementia**

##### **Aim:**

- Reduce the risk factors associated with long-term conditions
- Reduce the risks of developing complications from long-term conditions
- Improve care and support, and ultimately, outcomes for people with long-term conditions

##### **Commitments include:**

- Considering the experiences and needs of people with long-term conditions and their carers by working with them to develop services
- Support community resilience by ensuring that local services take into account the diversity of experience and background of people with long-term conditions and their carers
- Support the development of a health and care workforce that is agile and responsive to patient and community needs. This will include creating teams of professionals who can work across specialisms and signpost people to our community assets and facilities which can support people to improve their health and wellbeing

##### **Outcomes:**

I can access services which address all my needs and have an awareness of how my lifestyle, such as my housing situation, impacts my health and my access to services. My wider health needs, including accessing opportunities for physical activity, are addressed and supported.

I have input in the development of my care plan with my family and carers. My carers are supported to care for me and have their own needs recognised.

I have a named point of contact who understands me and my condition(s). I feel that the health and care services and staff I engage with understand my specific needs and listen to me.

I believe that the professionals involved in my care talk to each other and work as a team.

I am supported to remain independent and stay living in my own home.

## Central London CCG Primary Care Strategy

Central London CCG's Primary Care Strategy also includes a specific priority for better care for people with long-term conditions (Box 2). This will be achieved through improved joint working within General Practice and with other care services. An accountable care approach will be developed to provide a unified approach.

### Box 2: Central London CCG Primary Care Strategy

#### Central London CCG's vision

*"improve the quality of care for individuals, carers, and families, empowering and supporting people to maintain independence and to lead full lives as active participants in their community".*

#### Specific local priorities include:

- Improving health and wellbeing
- Better care for people with long-term conditions
- Better care for older people

#### These priorities will be delivered through:

A new approach to providing health and care that:

- Prioritises more joint working within general practice and with other care services wrapped around the registered lists of groups of practices

- From primary care upwards, develops an accountable care approach that underpins a unified approach to all care delivered within Westminster
- Increases payments based on outcomes rather than activity

## GP practices in the London Borough of Westminster

The London Borough of Westminster has 34 GP practices covered by Central London Clinical Commissioning Group. A further ten GP practices in Queen's Park and Paddington are covered by West London Clinical Commissioning Group. Each of these CCGs has commissioned a different type of primary care support for people living with long-term health conditions. Central London CCG commissions the Care Co-ordination Service provided by Central London Healthcare. Queen's Park and Paddington patients are covered by West London CCG's My Care, My Way provision.

### Care Co-ordination Service

The Care Co-ordination Service (CCS) provides administrative support for GPs and care navigation for patients in some practices. It provides care planning support for people with complex and long-term conditions. It replaces the Patient Referral System and all patients should be able to access it to assist them in booking referral appointments. Extra support through proactive care is provided to:

- Anyone over the age of 65 years
- Anyone over the age of 18 who has one or more long-term condition
- Anyone whose clinician agrees they would benefit from the service

The CCS provides support to 33 GP practices in Central London, divided into nine villages. Three villages were part of Wave 1 and received an enhanced service that included access to a Care Navigator who provided a social prescription function.

**Care Navigators** mostly contact patients by telephone; this is done at the request of the GP who remains responsible for that patient's care. Care navigators can link patients into local community and voluntary organisations to help them manage their long-term health condition. They can also contribute to preparing a care plan. They are not a named person for the patient to contact, although they may help to co-ordinate services.

We included a question in our survey that explored whether respondents had benefited from a range of options that mapped onto the tasks identified as being part of the Care Co-ordination Service commissioned by Central London CCG (Box 3).

However, not all survey respondents or focus group participants told us which GP surgery they were registered with and were not always aware of the names of the





service they receive, or which CCG was their local commissioner. As a result, it is not possible to be clear which provision was being referred to. Therefore, this report does not offer a view on how well the CCS is helping to support people living with long-term health needs.

### Box 3

Survey Question 3: Which of the following has your GP, or someone from your GP practice helped you with? Please tick all that apply.

- Help to create a care plan that was tailored to your health needs and goals
- Booking and co-ordinating your appointments
- Referring you to services identified in your care plan
- Being a single point of contact for all your referral, care plan and co-ordination queries
- Assisting you to better maintain and improve your health and wellbeing
- Contacting you regularly to see how you are getting on and providing encouragement
- Giving you extra support when you feel your health was getting worse and when you needed help to improve or maintain it
- Providing assistance for you when you are struggling to co-ordinate care for yourself
- Telling you about community-based wellbeing services or activities

### My Care, My Way

The London Borough of Westminster also includes the Queen's Park and Paddington area. This part of the borough contains about a quarter of the GPs in Westminster (ten) who come under West London CCG. Older patients can access My Care, My Way, which specifically supports the health and wellbeing of local people who are aged 65 and over to help keep them well, closer to home. It is a multi-organisation collaboration led by West London CCG and includes GP surgeries, hospitals, local community and social care services as well as local voluntary organisations.

Two respondents to our survey stated that they were registered at GP practice covered by West London CCG. One had been referred to My Care, My Way. This respondent had received physiotherapy, had been contacted at times when they needed some additional support and were visited by District Nurses twice weekly. They reported that it was easy for them to get the help they needed.

However, the other respondent registered at GP practice covered by West London CCG had received no support and reported that they found it very difficult to access the help they needed.



# 4. GP practice support for people living with long-term health conditions

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What type of help do patients with long-term health conditions receive from their GP practice?

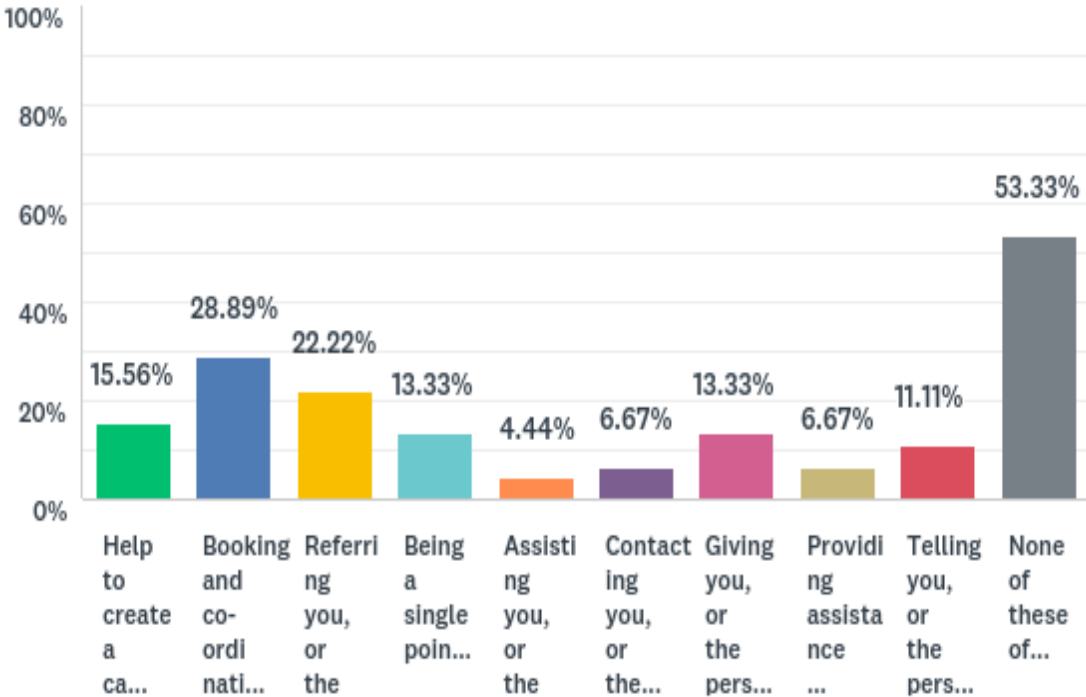
We asked people what type of support they received to help them manage their long-term health condition. In our survey we listed a range of different options based on those offered through the Care Co-ordination Service:

Support offered	Number of respondents out of 45
Help to create a care plan that was tailored to your health needs and goals	7
Booking and co-ordinating your appointments	13
Referring you to services identified in your care plan	10
Being a single point of contact for all your referral, care plan and co-ordination queries	6
Assisting you to better maintain and improve your health and wellbeing	2
Contacting you regularly to see how you are getting on and providing encouragement	3
Giving you extra support when you feel your health was getting worse and when you needed help to improve or maintain it	6
Providing assistance for you when you are struggling to co-ordinate care for yourself	3
Telling you about community-based wellbeing services or activities	5

None of the above	24
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As can be seen, **just over half** of all respondents **had not received any** of the options listed above. Over a quarter (28.9%) had had help with booking and co-ordinating appointments and just under a quarter (22%) had been referred to services in their care plan. In the focus groups, a number of participants stated that this had been better under the Patient Referral System.

Most notably, only two respondents had been offered help to maintain and improve their health and wellbeing. Only three had felt that they had received assistance when they were struggling to co-ordinate their own care or had been contacted to see how they were getting on.



Graph: What type of help do patients with long-term health conditions receive from their GP practice?

**Care Co-ordination Service Wave 1 Village GP practices**

As each of these tasks were identified as being part of the Care Co-ordination Service offered through all Wave 1 Village GP practices, we looked at what our

data could tell us about the support that people registered at these GP practices received.

Not all respondents to the survey informed us of which GP practice they were registered at; however, **12 did tell us that they were registered at GP practices in one of the Wave 1 Villages.**

**One** of the 12 respondents said they had received **all the support options** in the question; a further four respondents had received at least one of the options with help to book and co-ordinate appointments the most frequently chosen option.

However, **eight of the 12 people (66.6%)** registered with a GP practice in a Wave 1 Village had received **none of the options** set out and rated it as **difficult or very difficult** to get the support they need. This compares to just over half (53.3%) of all respondents as a whole.

We took a closer look at the open responses that the 12 people who were registered with GP practices in the Wave 1 Villages gave, to build up a more comprehensive picture of the type of support they were receiving and any difficulties they encountered.

### **Assistance to maintain health and wellbeing**

Concerns were raised about managing regular medication and about how well these were monitored:

- “I am currently struggling to get a medication review, after four years on the same dose and medication and it seems impossible.”

There were also questions about what health conditions can be managed through primary care and how patients with other conditions can be supported:

- “Not all long-term conditions and disabilities are included in primary care services. This is a real problem for those patients who live far from a hospital.”

### **Extra support when health is worsening**

We heard of some good experiences where people were able to access the help they needed:

- “I put easy rather than ok although it is not always easy to get an appointment to see the GP who knows me most. Having said that a doctor

will phone you on the day and see how to help me and will refer me on if necessary.”

However, others found it hard to get support when they were unwell:

- “Support is fine when health is reasonably good, but not so during a bad experience for 3 months - told ‘but you have an incurable progressive condition’.”

And worryingly, it appeared to be hard to get a home visit even when that was the advice they had received from NHS England:

- “Forced to attend GP appointments in winter when weather is just above freezing, which is against advice and alerts I get from NHS England via email..”
- “Unable to arrange an appointment at time of being unwell. Constantly refused home support including INR test by district nurse.”

There were also concerns about accessing a GP when needed at weekends:

- “When my (adult) son aspirates I need immediate help like antibiotics for chest infections as sometimes I have to wait weekends to pass then he has to be seen so it drags on and my son’s suffering is unbearable.”

### **Single point of contact**

The importance of having one person who knows and understands their health conditions was flagged:

- “She knows me, I trust her and can check things out with her. I don’t like to talk to loads of different people.”

### **Integration of health, care and community services**

We heard of some good experiences of where services had worked well together:

- “Staff are all helpful and considerate and always able to help me find what I need, for example information from the Maggie Centre at Charing Cross hospital.”
- “My GP is available to review the medicines after discharge of hospital with too many medicines as recommended by the Hospital and would refer to Secondary Health Care Team to review or prompt to take action.”

For others, their experiences were less positive:

- “No support at all as community services reserved for COPD and Asthma patients. I have breathing problems but not those, so nothing is there for me.”

We asked for more information on people’s experiences of support through their GP practice:

### **Assistance to maintain health and wellbeing**

Some people had good experiences of their GP helping them to maintain their health:

- “My GP knows me well and can see when I am not good. He always asks - ‘how are you, is there anything else you need?’ (Focus group participant).

Others were concerned about whether a GP was the right person to help with their condition:

- “Do GP’s have specialised knowledge on conditions? They lack the in depth understanding of Dementia”, (Focus group participant).

### **Integration of health, care and community support**

People discussed the **lack of integration or coordination between services**, stating that they had to call several services to get hold of one service:

- “I have been passed on from one service to another. GPs are unable to signpost people to the right kind of services, they don’t know what is available - how can they? I wish they did!”, (Focus group participant).
- “I had to make several phone calls before finding out my elderly mother needed to access an Admiral Nurse. I didn’t know about this, they could have just told me, but I had to keep ringing for help”, (Focus group participant).

There were also concerns that services did not seem to communicate well with each other:

- “The lines are not all joined up. I have to remember for my mother and follow up. There needs to be better communication between doctor, chemist and district nurses. For example, district nurses frequently turn up to see my

mother when she is at the day centre - they should collate information that is regular”, (Focus group participant).

- “Mum needed her feet doing, took a few calls and some confusion from GP to service, which mum only luckily got due to cancellation. Was a bit confusing and I (her daughter) had to chase it up. That service no longer available. Post stroke feet very important. The treatment was very helpful” (Survey respondent).

However, there were some positive experiences where support had been available following a hospital admission:

- “If you need help home visit district nurse they are good. Mum had a Neuro rehab team after hospital who were fantastic and most of ongoing stuff came from them”, (Survey respondent).
- “I see the GP for my prescription, they are supportive. Pharmacy delivers my prescription” (Focus group participant).

One person with a Central London CCG GP had heard from a friend about My Care, My Way:

- “West London CCG have a Care Navigator system that was co-produced by patients and carers, it is good”, (Focus group participant).

## Support for Care Plans

Care plans were discussed in each of the focus groups, with only two participants stating that they had a care plan:

- “I have a care plan that my GP arranged with me. I know him well, he has been my GP for 40 years, that is important, we know each other”, (Focus group participant).
- “I had a care plan from the hospital when I was discharged. My GP ignored it and said, ‘Oh no, you don’t need that’. GPs should listen to hospital consultants. The care plan was never used”, (Focus group participant).

Most focus group participants **did not know about care plans**, had never been offered one by their GP, and did not know how to get one:

- “What is a care plan, what does it cover?”, (Focus group participant).
- “How do I know if I should have one? No one has ever mentioned it to me, now I don’t know if I should ask!”, (Focus group participant).

## Single point of contact

The importance of having a single point of contact was mentioned to help manage different appointments and maintain focus:

- “As mum’s carer I organise everything and one point of contact would be helpful for all things. Once discharged from them it’s a matter of joining up dots and having energy to keep on it”, (Survey respondent).

However, the single point of contact needed to have some authority:

- “There is a new Healthcare Assistant in charge of care planning and now there is no priority for appointments for people over 75. It is hard to get help when I need it”, (Survey respondent).

### How Easy or Difficult is it for patients to get the support they need for their long-term health condition through their GP practice?

In our survey about a third of respondents said that it was Very Easy, Easy, or OK, two thirds said that it was Difficult, or Very Difficult.

Very Easy	13.33%
Easy	11.11%
OK	6.67%
Difficult	31.11%
Very Difficult	37.78%

We asked for more information on why they had picked each option in the survey and also discussed this in the focus groups. Those that found it **Very Easy, Easy, or OK** stated that:

- “My GP is very good and I’m one of the lucky ones”, (Survey respondent).
- “I get support when I need it”, (Survey respondent).
- “GPs are helpful on the phone but do not visit”, (Survey respondent).

For those who found it **Difficult, or Very Difficult**, their responses included:

- “GP has a busy surgery and they have too many people to see at any time, patients are given very little time individually”, (Survey respondent).

- “It’s currently very difficult to get any response from the GPs at the surgery I use at all. I am currently struggling to get a medication review, after four years on the same dose and medication, it seems impossible”, (Survey respondent).
- “Not all long-term health conditions and disabilities are included in primary care services. This is a real problem for those patients who live far away from a hospital”, (Focus group participant).

## What experiences did patients have in trying to get support for their long-term health condition through their GP practice?

We heard that some people had **good relationships with their GP**:

- “We talked about things; we know each other well”, (Survey respondent).
- “...if I need something my GP practice is very good if the GP knows my son very well (son has complex health needs). Sometimes with a new GP I have to explain a bit more, but I feel every GP should know my son’s condition without my explanation - it should be available for them in his records”, (Focus group participant).

## Attitude of staff working primary care settings

However, others had experienced **difficulties**. In the focus groups participants talked about the **attitude** of GPs, consultants, doctors in Urgent Care settings and other GP practice staff. One participant talked about hearing a Practice Manager openly saying that they did not believe in care co-ordination or double appointments for elderly patients. Others had similar experiences:

- “Doctors can have a poor attitude towards the elderly patients, we become a burden” (Focus group participant).
- “They say, ‘you are old, what do you expect?’ but I am trying to say this is something that I need them to do something about. They don’t listen” (Focus group respondent).
- “When I phone them or visit them on my mother’s behalf they seem surprised that she is still alive. She has a range of complex conditions. They do not know enough about Dementia, cannot help with mobility issues or support with her heart condition. They know nothing about what other support is out there in the community” (Survey respondent).
- “The person I care for complained that the GP does not look at them rather concentrate on the computer screen, it becomes tick box exercise rather than human contact. GP has busy surgery and they have too many people to see at any time, patients are given very little time individually” (Survey respondent).

## Booking appointments to see GP



In both the focus groups and telephone interview people talked about **difficulties making appointments**:

- “We can hardly get through to the phone to get appointments. We hang on for 30 to 45 minutes and when we get through, most of the time all appointments are gone, or our GP is not available. For 10,000 patients, there should be more than two people answering the phone”, (Survey respondent).
- “Making appointments is difficult. Queuing in the rain and cold with an exacerbation for 30 minutes for same day appointment. Phoning at 8am is permanently engaged. 111 said they did not have access to weekend appointments”, (Telephone interviewee).

The importance of seeing **the same GP**, who knows the patient was often mentioned in both the focus groups and the survey:

- “No one is giving me support so it is difficult. Takes months to see the same GP who knows me - this is important to me; they work part-time”, (Survey respondent).
- “It feels like people go through a system, there’s no personal touch. I want to see someone I know, who knows me”, (Focus group participant).

### **Pressure on GP’s time**

From the discussions in the focus groups it was clear that patients are aware of pressures that GP practices may be under:

- “GPs have a lot of patients on their books, no wonder it is hard to get an appointment”, (Focus group participant).
- “Care Co-ordinators are only at my GP surgery for one day each week and therefore have limited time, what can they do in that time?”, (Focus group participant).
- “Consultations with GPs are time limited and it’s difficult to discuss my health issue in detail”, (Focus group participant).

### **What did carers tell us?**

Amongst carers there was a high level of dissatisfaction with the support they received from their GP practice, with the general feeling being that there was limited provision available for them.

One participant’s mother who was in her 90s and has Dementia, lives in Westminster but she herself lives in the North of England, travelling to care for her mother three times a week. She is not considered a carer by her own GP because her mother lives in a different area, so she receives no support for her caring role. She has been unable to access support for carers local to her mother in Westminster.

- “My mother’s GPs have provided very little support; I had a call from a ‘care navigator’ only once. The issue raised with the care navigator was about making adaptations in the property. The care navigator’s response was that it was not within their remit; they didn’t tell me where I could access help. There was no signposting. I finally got information to contact the Occupational Therapy team through another source”, (Focus group participant).
- “We get ignored by the GP. We don’t have access to medical records and if they (GPs) don’t talk directly to us, then we don’t have the information either. My husband won’t always tell me what I need to know - so what am I meant to do?”, (Focus group participant).

Carers also told us through the survey that it was hard for them to get the help they needed through their GP surgery:

- “I’m the carer. I feel that the GP and all concerned leave too much up to me. I feel that there should be better co-ordination and it should not all fall on my shoulders”, (Survey respondent).
- “Referrals have long waiting lists. GP surgery is always busy. GP waits for a crisis situation before the matter is taken seriously. The person I care for has been complaining about black outs and irregular heartbeat, but GP did not take any action, they had a seizure and ended up in hospital. If action was taken sooner and they were taken seriously, perhaps the hospital admission could have been prevented”, (Survey respondent).
- “Soldiering on month after month, year after year, managing care for my husband is very demoralising. I am over 70 myself and wonder how much longer before my own health degenerates” (Survey respondent).

One carer in a focus group did say that the GP surgery had been helpful as the person he cared for had Dementia. He also got support for himself as a carer. However, he had been registered with the surgery for 40 years and had a positive relationship with the doctor.

### **Support for mental health conditions and wellbeing**

How well people’s mental health and wellbeing was supported by their GP practice was mentioned. We heard that people struggled to get help when it was needed and at times got sent from one service to another, with the GP unable to meet their needs:

- “It’s hard to write about. My diabetes services are WELL co-ordinated. Not so mental health services re. my partner’s apparent early onset Dementia (still uncertain what’s going on). I feel like we have been left dangling, offered self-referral to IAPT”, (Survey respondent).
- “They aren’t much help and we get pushed from GP to local mental health care providers - ‘oh that’s a physical problem’; ‘oh that’s a mental health problem’. Person needs to be treated as a WHOLE”, (Focus group participant).

- “I recently contacted Mind for help with depression as GP request for this was not forthcoming”, (Survey respondent).

## **What support do patients with long term health conditions expect from their GP practices?**

We asked people attending the focus groups what could change to make the support they receive through their GPs better. The discussions were wide ranging, but there was some agreement:

### **Communication and information**

There were concerns raised about GPs and consultants not communicating well with each other and at times disagreeing on diagnosis. In addition, communication from the GP surgery to patients can be poor and information given not helpful:

- “I received a booklet from my GP surgery on physiotherapy. The booklet was really badly designed and was not useful.”

Face-to-face support was not always available, with more support now being offered over the phone or through booklets/written information. This meant that not all diagnosis could be discussed in detail.

There was also general consensus that people should take personal responsibility for managing their own health conditions, but that support was needed to help with this. GP practices need to operate in a way that supports this, including sending reminders for appointments in formats that are accessible to the patient. The focus groups were split on whether a text message was useful for this, suggesting that patients need to be offered a choice.

Furthermore, there was a demand for more information on how to self-manage their conditions and where to get additional support.

### **Involving patients**

Patient Participation Groups (PPGs) were flagged as ways for patients to really make a difference to what services and support was on offer at their GP practice. However, very few participants were aware of PPGs and did not know how to contact theirs. Amongst those that were part of the PPG at their GP practice, there was a view that they were not well supported, and that Practice Managers need to know that they should put resources into them:

- “I attend my PPG but there’s normally only three of us and nothing changes. They just give us a room then don’t listen to what we say.”

## Integration of health, care and community support

There was frustration that different services were not talking to each other, resulting in people having two or more appointments booked at the same time, in different locations. Or having appointments for different clinics at the same place but on different days:

- “It’s hard for me to get the bus there, then it’s a bit of a walk. Why do I have to go three times in one week when I could do them all on one day? They are right next to each other!”

Focus group participants had not heard of ‘social prescribing’ and there had been little information given to people about community or voluntary services that could help them manage their health condition, or support their mental wellbeing:

- “Some weeks I don’t go out for days at a time. There must be things I could do but I don’t know. Those are the days I hate, makes my feet hurt more - no distraction see.”

### A single point of contact

There was a general consensus that the single thing that would make the most difference would be to have a named person who could be contacted when more help was needed or when information about their condition was needed:

- “Mostly I manage, I get by, but those times when I’m not managing, or my prescription has changed, or I have a new thing going on, then I really want someone I can just ring or drop in to see. Someone who knows me and what I’ve been through.”

### Peer support

There was interest in local peer to peer support possibilities for patients with specific conditions, with some oversight from the GP practice. This would allow people to share their experiences and learn from each other:

- “I’ve learnt more from being at this focus group and talking to other people than I ever do at the doctors! We’re all kept apart but we could help each other - all we need is a room. And a cup of tea and biscuits!”

# 5. *What would help patients and carers manage their long-term health conditions better?*

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Focus groups participants had plenty of thoughts on what could change to make the support they receive through their GPs better:

- “Better communication for those over the age of 75’s - a letter can be sent annually to those over the age of 75 with all the necessary information such as vaccines or other services they are entitled to.”
- “A Yearly Health MOT check for patients over the age of 75.”
- “GP’s should prioritise the elderly and offer support to make appointments.”
- “All GP surgeries need to have some standard practices about how services are co-ordinated.”
- “Dedicated time for consultation with the doctor so that you’re not being rushed.”
- “Patients with long-term health conditions can be sent a letter with information on services available, and not just health services, all the other wellbeing ones as well.”
- “Linking together all wellbeing services and letting patients know about them, including nutrition and exercise.”
- “To look after my mental wellbeing alongside my physical health.”
- “A named Co-ordinator based with my GP who I can contact directly and meet with if I need to.”
- “Someone to talk to after the consultation so I can check that I have understood and know what I need to do.”
- “It would be good to get reminders from GP surgeries to make appointments.”

- “A care plan should include practical support. It should also include an indication of what health changes to expect and forward planning for progressive conditions for carers.”
- “Carers need their own care navigator, who looks out for their support needs.”

## Conclusions and Recommendations

This report aimed to provide a picture of the experiences of people living with long-term health conditions and their carers in Westminster. The main questions explored are:

- What type of support patients received through their GP practice to help them manage their long-term health condition; and
- How easy it was for patients to get the help they need for their long-term health condition through their GP practice.

We heard mixed experiences of the type of support available through GP practices to support people to manage their long-term health conditions. It was very apparent in focus group discussions that the support on offer varied depending on which GP practice participants were registered at.

We heard that some patients and carers have good experiences of receiving help to manage long-term health conditions. The relationship built up with the GP and having a personalised response to their health or care needs seemed to be key to this.

However, two-thirds of our survey respondents said that they found it hard to get the help they needed to manage their long-term health condition from their GP practice. They, and the focus group participants highlighted a range of difficulties that they encountered.

As local health systems are changing in Westminster through Central London CCG’s proposed Primary Care Strategy and the development of different accountable care partnerships to deliver a more integrated health and care offer for local residents, it is important that the voices of patients and carers are kept central to considerations of new ways of working, and when commissioning and evaluating services. We have heard from patients and carers about their experiences of living with, or caring for someone with, a long-term health condition in the borough of Westminster and their aspirations of how the health care and support they receive could be improved.

## 1. Clear patient pathway

Patients and carers would like services to work better together. Patients and carers manage their different appointments themselves and medical professionals are not always aware of other clinicians involved with the healthcare of the patient.

Patients and carers also wanted medical professionals to be better at communicating with each other: to share information about individual patients so that support was better co-ordinated; to inform each other what their role was; and to be clear what the service they worked for could offer.

Patients and carers would like more information about health and wellbeing support available from community and voluntary organisations. This support could help them better manage their, or the person's they care for, health conditions. It could also help them build relationships with others in their local community with whom they could share information, offer support and reduce their isolation.

Managing a long-term health condition requires patients and carers to have good, accessible and clear information about their health condition and what help is available. This includes information about how their, or the person they care for, health condition is likely to progress and how to get additional support when it is needed.

Patients and carers told us that the single thing that would make the most difference to how well they were able to manage their long-term health condition would be to have a named person who could be contacted when more help was needed or when they needed more information about their health condition.

**Recommendation 1:** GP practices give patients and carers with long-term health conditions clear information about the support they will receive to help them manage their health condition.

This should include information on:

- Who is eligible to receive additional support to help them manage their long-term health conditions
- What support can be offered through the GP practice
- How to ask for extra support to manage a long-term health condition from their GP practice
- How their GP will consult with them to help them to identify what help they need and what support is available.
- How the GP and other health and care professionals will ensure a personalised approach is taken so that the patient is in charge of the care they receive to manage their long-term health condition
- How the GP practice will co-ordinate their care with other healthcare professionals and how this will be communicated to the patient



Once a patient is receiving additional support, their care plan should clearly state:

- Who their named contact is that they can go to for further information and advice. Any changes to this should be clearly communicated to the patient
- Details on how to contact their named healthcare professional
- Information about their long-term health condition and self-care advice
- What health and care services they are receiving and how to contact them
- How to access other local community support and resources

## 2. Patient Participation Groups

Patients and carers would like to be more involved in deciding and evaluating what help was available for people with long-term health conditions through the GP practice. People wanted to be asked their opinions about what support was on offer and what could be done differently.

When informed about Patient Participation Groups (PPGs), many focus group participants felt that these would be good fora for them to feed in information about their experiences of the support available at their GP practice and to express an opinion on what could be changed to improve provision.

**Recommendation 2:** GP practices are supported by the CCG to develop PPGs in their practice and to demonstrate how they have listened to patients and carers, and made changes based on their experiences.

**Recommendation 3:** Recruitment and engagement of new and existing PPG members should target patients with long-term health conditions and their carers.

**Recommendation 4:** PPG members should be given opportunities to share their experiences at a wider CCG level through engagement in the new Primary Care Homes as they are formed so that patient experience is used to shape service provision, communication and improvements.

## 3. Support for mental health conditions and wellbeing

Patients and carers struggled to get help for their mental health and wellbeing when it was needed and at times got sent from one service to another, with the GP unable to meet their needs.

**Recommendation 5:** Patients with long-term health conditions and their carers are regularly asked about their mental wellbeing and are referred to mental health support where needed and signposted to community and voluntary organisations that offer services to support mental wellbeing.

## 4. Carers





The carers we spoke to were caring for relatives and friends with a range of health needs. The people they were caring for tended to need a high level of support and were accessing a number of different health services. Carers told us that they were expected to co-ordinate a lot of the care themselves and did not feel that they had enough information of support to do this.

None of the carers we spoke to had had their own needs assessed and they reported that they would like to have someone who was looking after their own health and wellbeing.

**Recommendation 6:** All carers for people with long-term health conditions should be offered a named professional based in the GP practice, with clear information on how they can be contacted, focused on supporting their own health and mental wellbeing.

## 5. Attitude of staff working in primary care settings

The negative and unhelpful attitudes that both patients and carers experienced from staff working in a range of primary care settings, including GP practices adds to the difficulties they face in managing their, or the person's they care for, long-term health condition.

**Recommendation 7:** Staff across the range of provision in GP practices should be regularly reminded of their responsibilities under guidance from NHS England on how to support long-term conditions to ensure that people with long-term health condition have access to home visits, medication reviews, etc. to support a good quality of life.

# 6. *What happens next?*

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Under the Health and Social Care Act 2012 Healthwatch CWL has a statutory duty to:

1. Promote and support the involvement of local people in the commissioning, the provision and scrutiny of local care services.
2. Enable local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.
3. Obtain the views of local people regarding their needs for, and experiences of, local care services and importantly to make these views known.



4. Make reports and recommendations about how local care services could or ought to be improved.

These should be directed to commissioners and providers of care services, and people responsible for managing or scrutinising local care services and shared with Healthwatch England. In line with these duties a copy of this report will now be circulated to the following organisations:

- Central London Clinical Commissioning Group;
- Central London Healthcare;
- Westminster Scrutiny Committee;
- Westminster Health and Wellbeing Board;
- The Care Quality Commission
- Healthwatch England

## 7. Appendix

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Survey



**When it comes to managing your health condition, do you get the support that you need from your GP practice?**

Healthwatch Central West London and the Older Adults Group at the Advocacy Project want to know more about how well people living in Westminster are supported by their GP practice to manage health conditions that last longer than six months.

We will use the answers you give us in this survey to tell GPs and health commissioners how well people with longer term health conditions are being supported to manage their conditions.

Where improvements are needed, we will make recommendations for change.

Thank you for taking the time to share your experiences, we will make sure that they are heard by those with the power to make a difference.

If you would like more information, please contact Carena Rogers, Healthwatch Central West London Engagement Coordinator for Westminster:

[carena.rogers@healthwatchcentralwestlondon.org](mailto:carena.rogers@healthwatchcentralwestlondon.org)

## Survey questions

1. Please tell us what health condition(s) you, or the person that you care for, have

2. How long have you, or the person you care for, had your health condition(s) for?

- Less than 6 months
- 6 months to a year
- More than a year
- More than 3 years

3. Which of the following has your GP, or someone from your GP practice helped you with? Please tick all that apply.

- Help to create a care plan that was tailored to your, or the person you care for, health needs and goals
- Booking and co-ordinating your, or the person you care for, appointments
- Referring your, or the person you care for, to services identified in your care plan
- Being a single point of contact for all your, or the person you care for, care plan and co-ordination queries
- Assisting your, or the person you care for, in better maintaining and improving your health and wellbeing
- Checking in with your, or the person you care for, regularly to see how you are getting on and providing encouragement

- Giving extra support for your, or the person you care for, extra support when you feel that your health was getting worse and when you needed help to improve or maintain it
- Providing assistance for your, or the person you care for, when you are struggling to co-ordinate care for yourselves/someone you care for
- Telling your, or the person you care for, about community based wellbeing services or activities
- None of these options

4. Do you feel that it is easy or difficult to get support for you, or the person you care for, health condition(s) from your GP practice if you need it?

- Very easy
- Easy
- OK
- Difficult
- Very difficult

Please tell us why you chose this option:

Does your GP practice offer any other support for people with long term health conditions that is not part of the Care Co-ordination Service?

- Yes
- No
- Unsure

Is there anything else you would like to tell us about support for people with long term health conditions living in Westminster? Please tell us in the box below

Thank you for taking the time to fill in this survey.

If you would like more information, or would like to tell us more about your experiences of supporting people with long term health conditions in Westminster, please contact Carena Rogers, Healthwatch Central West London Engagement Coordinator for Westminster:

[carena.rogers@healthwatchcentralwestlondon.org](mailto:carena.rogers@healthwatchcentralwestlondon.org)

### **Information on the Care Co-ordination Service**

The Care Coordination Service (CCS) is provided by Central London Healthcare. It aims to provide patients with extra support when they need it. They do this by making a plan with the patient for their future care that centres on *their* goals for their health and well-being as well as what actions the patient can take to achieve these themselves.

The CCS works with the GP Practice to

- Help create care plans tailored for patients' needs and goals
- Booking and co-ordinating patients' appointments
- Referring patients to services identified in their care plan
- Being a single point of contact for all the patient's referral, care plan and co-ordination queries
- Assisting patients in better maintaining and improving their health and wellbeing
- Checking in with patients regularly to see how they are getting on and providing encouragement
- Giving extra support for those who feel that their health is getting worse and needs help to improve or maintain it
- Providing assistance for anyone who is struggling to co-ordinate care for themselves/someone they care for

### **Who is eligible for the Care Co-ordination Service?**

- Anyone over the age of 65 years
- Anyone over the age of 18 who has one or more long-term condition

- Anyone whose clinician agrees they would benefit from the service

**Contact details:**

If you would like to find out more about the Care Co-ordination Service, please ring 0333 200 1234 or email [clh.ccs@nhs.net](mailto:clh.ccs@nhs.net)

DRAFT

# 7. Contact us:

## Get in Touch

Healthwatch Central West London 5.22 Grand Union Studios  
332 Ladbroke Grove  
London, W10 5AD

Website: [www.healthwatchcwl.co.uk](http://www.healthwatchcwl.co.uk)

Email: [info@healthwatchcentralwestlondon.org](mailto:info@healthwatchcentralwestlondon.org) Phone: 020 8968 7049

## Social media

Twitter: [@healthwatchcwl](https://twitter.com/healthwatchcwl)

Facebook: [www.facebook.com/HWCWL](https://www.facebook.com/HWCWL) Instagram: [@healthwatchcwl](https://www.instagram.com/healthwatchcwl)

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City of Westminster

## Westminster Health & Wellbeing Board

<b>Date:</b>	24 <sup>th</sup> May 2018
<b>Classification:</b>	General Release
<b>Title:</b>	Children and Young People with Special Educational Needs and Disabilities (SEND) – Joint Strategic Needs Assessment (JSNA)
<b>Report of:</b>	Director of Public Health
<b>Wards Involved:</b>	All
<b>Policy Context:</b>	To support the Health and Wellbeing Board statutory duty to deliver a Joint Strategic Needs Assessment
<b>Financial Summary:</b>	There are no financial implications arising directly from this report. Any future financial implications that may be identified as a result of the review and re-commissioning projects will be presented to the appropriate Board and governance channels in a separate report
<b>Report Author and Contact Details:</b>	Colin Brodie <a href="mailto:cbrodie@westminster.gov.uk">cbrodie@westminster.gov.uk</a>

### 1. Executive Summary

- 1.1 This report presents the final draft of the JSNA on Children and Young People with Special Educational Needs & Disabilities (SEND). The Board are asked to consider and approve the report for publication

### 2. Key Matters for the Board

- 2.1 The Health and Wellbeing Board are asked to consider and approve the report for publication.
- 2.2 Members of the Board are requested to send any comments or feedback on the report to Colin Brodie at [cbrodie@westminster.gov.uk](mailto:cbrodie@westminster.gov.uk) by 5pm on Friday 11<sup>th</sup> May.

### 3. Background

- 3.1 The JSNA describes a picture of need and service provision for children and young people with special educational needs and/or disabilities across Westminster. The JSNA was commissioned in order to inform the development of the joint Local Authority and Clinical Commissioning Group SEND Strategy for the Bi-borough. It will also be used to inform a SEND inspection by Ofsted which is expected imminently.
- 3.2 Public Health, Children's Services and the CCGs have worked in partnership to draw together data and evidence from a range of sources, including the views of parents and professionals working in the field.
- 3.3 The following key points provide an overview of the SEND population in Westminster. For further information on specific conditions please visit the relevant chapter in the JSNA which describes what we know nationally and locally.
- 3,641 pupils in Westminster schools have a special educational need (16% of state funded primary, secondary and special school population)
  - 6,290 children and young people in Central London CCG, 12% of the 0-25 CCG population, are known to their GP to have a SEND need (November 2017). This is a higher figure than number of pupils as it includes young people up to the age of 25; mental health conditions in young adults post school years; and may also include children and young people who attend private schools.
  - There are 3,220 children aged 3 and 4 benefitting from funded early education, of these 1.3% have an EHC plan and 5.9% are receiving SEN support. This is broadly in line with inner London.
  - 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 Westminster (43% 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 Westminster (29% of state-funded secondary school pupils with SEN)
- Westminster has slightly higher participation in education or training amongst 16-17 year olds with SEND (93%) than the London or national average
- Only 60% of Education, Health and Care Plan assessments in Westminster were conducted within the statutory time of 20 weeks (in 2017), however this has improved on 35% in 2016, compared to 48% across London.
- NICE guidelines state the autism diagnostic assessment should start within three months of the referral to the autism team<sup>1</sup>. Waiting times for referral to diagnosis of ASD were over a year in 2017/18 in the south Westminster for over 4.5 years of age, and 41 weeks from referral in centre and north Westminster.

3.4 A number of gaps and challenges have been identified which can be taken forward in the local strategy. These are described fully in the Executive Summary along the following themes:

- Early identification, diagnosis and post diagnosis support
- Information and signposting
- Service provision
- Transition
- Wider impact
- Further research

3.5 The SEND JSNA has been presented to the Children and Families Act Executive, the Cabinet Member for Adult Social Care and Health, and the Cabinet Member for Children, Families and Young People.

## 4. Legal Implications

4.1 The JSNA was introduced by the Local Government and Public Involvement in Health Act 2007. Sections 192 and 196 Health and Social Care Act 2012 place the duty to prepare a JSNA equally on local authorities (LAs), Clinical Commissioning Groups (CCGs) and the Health and Wellbeing Boards (HWB).

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<sup>1</sup> [National Institute for Health and Care Excellence: Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#)

4.2 JSNAs are a key means whereby LAs work with CCGs to identify and plan to meet the care and support needs of the local population, contributing to fulfilment of LA s2 and s3 Care Act duties.

4.3 Implications verified/completed by: Kevin Beale, Principal Social Care Lawyer, 020 8753 2740.

## **5. Financial Implications**

5.1 There are no financial implications arising directly from this report. Any future financial implications that may be identified as a result of the review and re-commissioning projects will be presented to the appropriate board & governance channels in a separate report.

5.2 Implications verified/completed by: Richard Simpson, Finance Manager – Public Health, 020 7641 4073.

**If you have any queries about this Report or wish to inspect any of the Background Papers please contact:**

**Colin Brodie, Knowledge Manager, Public Health**

**Email: [cbrodie@westminster.gov.uk](mailto:cbrodie@westminster.gov.uk)**

**Telephone: 02076424632**

### **APPENDICES:**

None

### **BACKGROUND PAPERS:**

Children and Young People with Special Educational Needs and Disabilities, Joint Strategic Needs Assessment (JSNA) Report.

# Children and Young People with Special Educational Needs and Disabilities

Joint Strategic Needs Assessment (JSNA) Report

Westminster City Council

Central London Clinical Commissioning Group

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 complex needs 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. Interviews were conducted with key stakeholders and providers.

## **Authors and contributors**

This report was written by Catherine Handley, Jessica Nyman, Colin Brodie, Charlotte Healy, Naomi Potter, Jonathan Pearson-Stuttard, with support from, Steve Comber, Steve Buckerfield, Jo Baty, Alison Markwell and Grace Parker.

## **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

<b>1</b>	<b>Executive summary of the JSNA</b>	<b>5</b>
1.1	Main findings.....	5
1.2	Key messages .....	6
<b>2</b>	<b>Introduction</b>	<b>10</b>
2.1	Summary of legislation and guidance .....	10
2.2	Local strategies.....	12
<b>3</b>	<b>Overview of SEND population</b>	<b>13</b>
<b>4</b>	<b>Special educational needs in education</b>	<b>16</b>
4.1	Early years .....	16
4.2	School years .....	20
4.3	Transition years and outcomes post 16 .....	25
<b>5</b>	<b>Pathway to support</b>	<b>27</b>
5.1	Special educational needs support and Education, Health and Care Plans.....	27
5.2	Diagnosing complex needs.....	29
5.3	Referrals to the Child Development Service in the centre and north of Westminster.....	29
5.4	Referrals to the Chelsea and Westminster Hospital NHS Trust Child Development Service.....	31
<b>6</b>	<b>Conditions in detail</b>	<b>34</b>
<b>7</b>	<b>Speech, language and communication needs (SLCN)</b>	<b>34</b>
7.1	Background .....	34
7.2	What do we know nationally? .....	34
7.3	What do we know locally? .....	35
7.4	What works .....	38
<b>8</b>	<b>Social, Emotional and Mental Health (SEMH)</b>	<b>41</b>
8.1	Background .....	41
8.2	What do we know nationally? .....	41
8.3	What do we know locally? .....	41
8.4	What works? .....	42
	44	
<b>9</b>	<b>Specific Learning Difficulties</b>	<b>45</b>
9.1	Background .....	45
9.2	What do we know nationally? .....	45
9.3	What do we know locally? .....	46
9.4	What works? .....	47

<b>10 Learning disabilities</b>	<b>49</b>
10.1 Background .....	49
10.2 What do we know nationally? .....	49
10.3 What do we know locally? .....	50
10.4 What works? .....	52
<b>11 Autism</b>	<b>54</b>
11.1 Background .....	54
11.2 What do we know nationally? .....	54
11.3 What do we know locally? .....	54
11.4 What works? .....	55
<b>12 Physical Disabilities</b>	<b>58</b>
12.1 Background .....	58
12.2 What do we know nationally? .....	58
12.3 What do we know locally? .....	59
12.4 Sensory impairments .....	60
<b>13 Long term health conditions</b>	<b>63</b>
13.1 Asthma .....	64
13.2 Diabetes .....	64
13.3 Epilepsy .....	65
<b>14 Social Care</b>	<b>66</b>
14.1 Background .....	66
14.2 What do we know nationally? .....	66
14.3 What do we know locally? .....	67
<b>15 Parents and carers of children with complex needs</b>	<b>72</b>
15.1 What do we know nationally? .....	72
15.2 What do we know locally? .....	73
<b>16 Appendices</b>	<b>75</b>
16.1 Appendix 1: Engagement .....	75
16.2 Appendix 2: Services .....	76
16.3 Appendix 3 – Guidance .....	77
<b>17 Bibliography</b>	<b>78</b>



## 1 Executive summary of the JSNA

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.

Westminster 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). The Local Authority is leading on a SEND Action Plan in partnership with schools and the joint commissioning plan has highlighted speech and language as a priority. The SEND strategy will address the challenges highlighted in this needs assessment. 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, and 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. Working in partnership, public health, children's services and the CCGs have together drawn on data and evidence 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 Westminster. 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 Westminster. For further information on specific conditions please visit the relevant chapter which describes in brief what we know nationally and locally.

- 3,641 pupils in Westminster schools have a special educational need (16% of state funded primary, secondary and special school population)
- 6,290 children and young people in Central London CCG, 12% of the 0-25 CCG population, are known to their GP to have a SEND need (November 2017). This is a higher figure than number of pupils as it includes young people up to the age of 25; mental health conditions in young adults post school years; and may also include children and young people who attend private schools.

- There are 3,220 children aged 3 and 4 benefitting from funded early education, of these 1.3% have an EHC plan and 5.9% are receiving SEN support. This is broadly in line with inner London.
- 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 Westminster (43% 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 Westminster (29% of state-funded secondary school pupils with SEN)
- Westminster has slightly higher participation in education or training amongst 16-17 year olds with SEND (93%) than the London or national average
- Only 60% of Education, Health and Care Plan assessments in Westminster were conducted within the statutory time of 20 weeks (in 2017), however this has improved on 35% in 2016, compared to 48% across London.
- NICE guidelines state the autism diagnostic assessment should start within three months of the referral to the autism team<sup>1</sup>. Waiting times for referral to diagnosis of ASD were over a year in 2017/18 in the south Westminster for over 4.5 years of age, and 41 weeks from referral in centre and north Westminster.

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<sup>1</sup> [National Institute for Health and Care Excellence: Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#)

## 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
<p><b>Early identification, diagnosis and post diagnosis support</b></p>	<ul style="list-style-type: none"> <li>• 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</li> <li>• 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.</li> <li>• 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</li> </ul>
<p><b>Information and signposting</b></p>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• 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</li> </ul>
<p><b>Service provision</b></p>	<ul style="list-style-type: none"> <li>• 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, 13% of the population moved out of the borough (including</li> </ul>

	<p>1,448 aged 0-24) and 11% of the population moved in (including 1,522 aged 0-24, in 2016).</p> <ul style="list-style-type: none"> <li>• 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</li> <li>• 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)</li> </ul>
<b>Transition</b>	<ul style="list-style-type: none"> <li>• 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</li> <li>• 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:             <ul style="list-style-type: none"> <li>• High Functioning Autism</li> <li>• Complex needs and requiring medical interventions</li> <li>• SLCN</li> <li>• PMLD</li> </ul> </li> </ul>
<b>Wider impact</b>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Children and young people with SLCN are less likely to progress into college education, more likely to experience unemployment,</li> </ul>

	<p>and more likely to have contact with the youth justice system. A Local Authority led SaLT Task &amp; Finish Group has been created which aims to establish a SaLT pathway, it is recommended the group address these challenges.</p>
<p><b>Further research</b></p>	<ul style="list-style-type: none"> <li>• There is a higher percentage of children across the three boroughs 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</li>   <li>• 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.</li>   <li>• A comprehensive and combined SEND database, across education, health and care, similar to Warwickshire’s database, would help plan for the future</li> </ul>

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## 2 Introduction

The [Special Educational Needs and Disability \(SEND\) Code of Practice](#) (January 2015), co-published by the Department for Education and the Department of Health, 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 Westminster, attending school in Westminster and those registered with a GP within the central CCG boundary. 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 be 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 (EHCP). Since 1<sup>st</sup> 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 ([Health & Wellbeing Boards SEND Guidance](#)).

### 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.<sup>2</sup>

### Duties under the NHS Act 2006

Under Part 1, section three: Provision of particular services, 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 [Transition from children's to adults' services for young people using health or social care services](#) (February 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.

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<sup>2</sup> [Council for disabled children](#)

## 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.

Local [Joint Health and Wellbeing Strategies](#) (2017-22) have given precedence to fulfilling the requirements of the Children and Families Act. One of the boroughs' four shared 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.

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### 3 Overview of SEND population

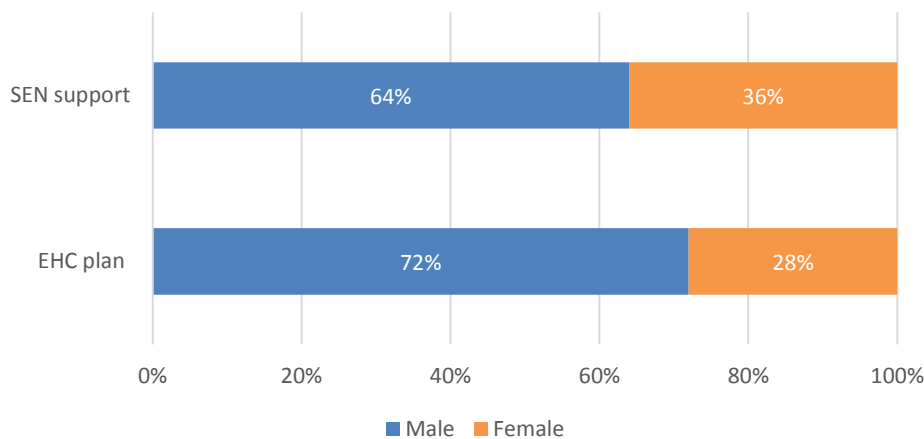
For information on the general population context please visit [jsna.info](http://jsna.info)

- There are 71,034 children and young people aged 0-25 in Westminster<sup>3</sup>
- There are 6,290 children and young people known to their GP within the Central (Westminster) CCG boundary with SEND needs including: autism, learning disabilities, physical disabilities, sensory impairments, mental health, asthma, epilepsy and diabetes (November 2017)<sup>4</sup>
- There are 273 2, 3 & 4 year olds with special educational needs (7% of total children benefitting from funded early education)
- There are 3,641 pupils with special educational needs, approx. 16% of the school population
- There are 1,013 children and young people for whom the local authority maintains a statement of SEN, or EHC Plan. 1% of children and young people who live in Westminster with statements or EHC plans are educated elsewhere

#### 3.1.1 Gender

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

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



Source: [Special educational needs in England, January 2017](#)

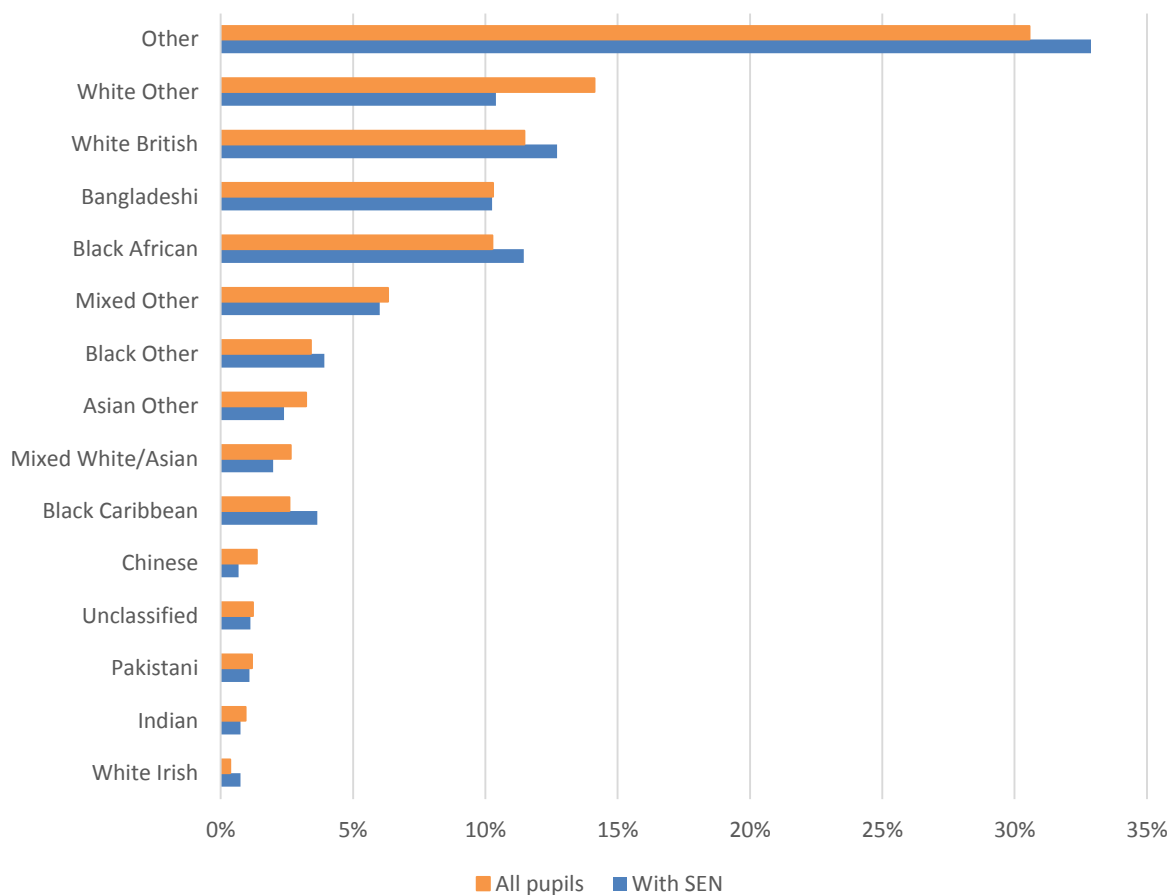
#### 3.1.2 Ethnicity

There are proportionately higher white British, black African and ‘other’ pupils with SEN, compared to the population as a whole. There is also a lower proportion of white other pupils.

<sup>3</sup> Mid-year estimates 2016 (published June 2017)

<sup>4</sup> System One and QOF data from Central CCG

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



Source: Westminster school census, January 2017

### 3.1.3 Deprivation

Poverty is both a cause and effect of Special Educational Needs and Disabilities (SEND).<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup>

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 and Platt, 2013).

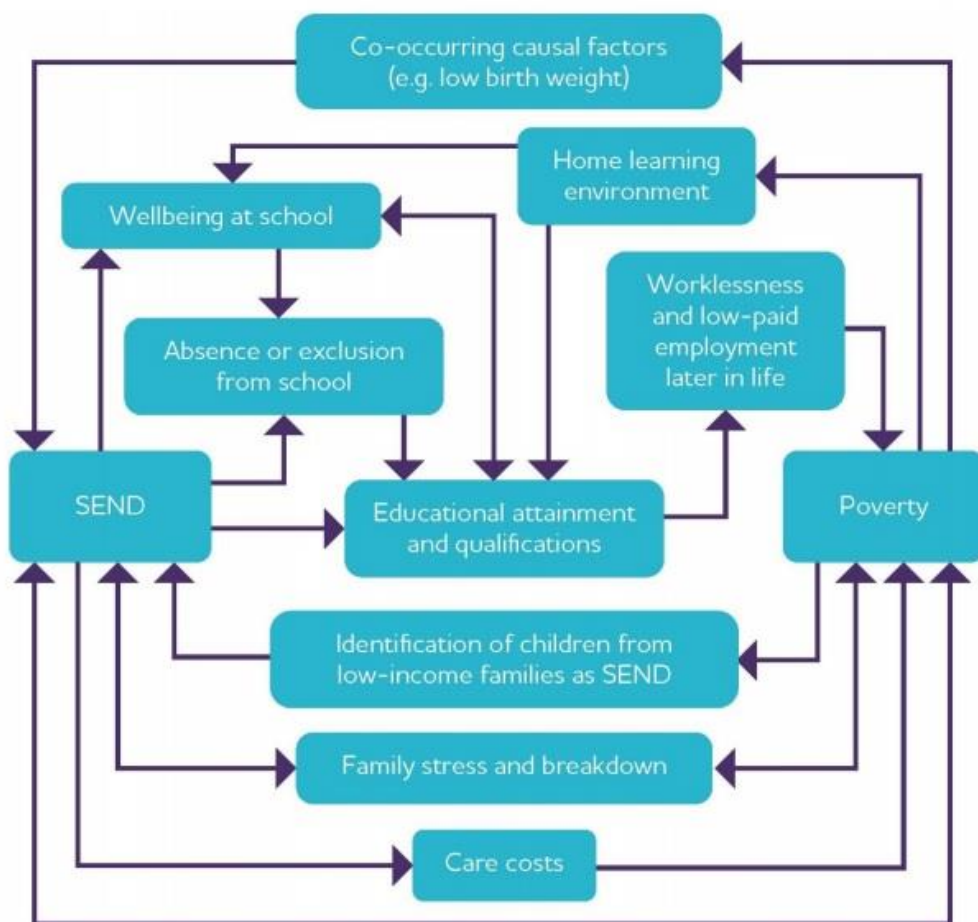
<sup>5</sup> [Special educational needs and their links to poverty](#), Bart Shaw, Eleanor Bernardes, Anna Trethewey and Loic Menzies, 26th Feb 2016, Joseph Rowntree Foundation

<sup>6</sup> [Special educational needs and their links to poverty](#), Bart Shaw, Eleanor Bernardes, Anna Trethewey and Loic Menzies, 26th Feb 2016, Joseph Rowntree Foundation

<sup>7</sup> Parsons and Platt, (2013). Parsons, S and Platt, P. (2013) *Disability among young children: Prevalence, heterogeneity and socio-economic disadvantage*. London Institute of Education, University of London

Westminster 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.<sup>8</sup>

#### 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.

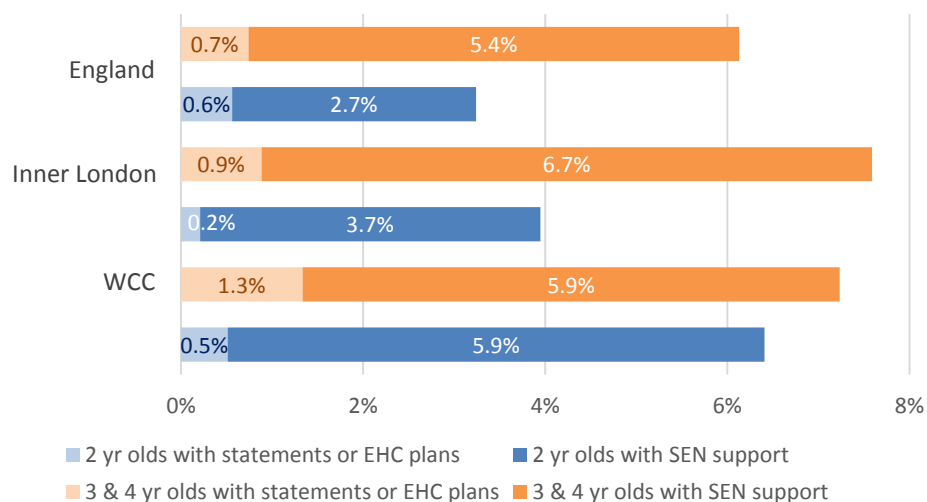
**2 year olds:** There are 390 children aged 2 that are benefitting from funded early education in Westminster. Of these, two have an EHC plan (0.5%) and 23 are receiving SEN support (5.9%). Westminster is in line with inner London and the national average for children with EHC plans, and slightly above the average for children receiving SEN support (Westminster: 5.9%, inner London: 3.7%, England: 2.7%).

**3 & 4 year olds:** There are 3,220 children aged 3 and 4 that are benefitting from funded early education in Westminster. Of these, 43 have an EHC plan (1.3%) and 190 are receiving SEN support (5.9%). Westminster has slightly smaller percentage of children receiving SEN support than inner London (5.9% vs 6.7%).

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<sup>8</sup> [Special educational needs and their links to poverty](#), Bart Shaw, Eleanor Bernardes, Anna Trethewey and Loic Menzies, 26th Feb 2016, Joseph Rowntree Foundation

Figure 4: Percentage of 2, 3 and 4 year old children that are benefitting from funded early education, that have special educational needs 2017

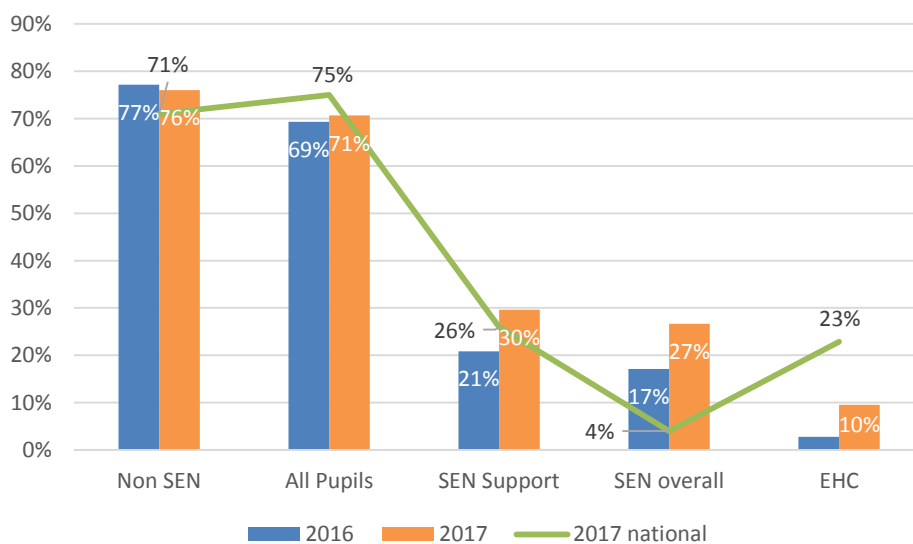


Source: [DfE Statistics - Provision for children under 5 years of age in England, 2017](#)

#### 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

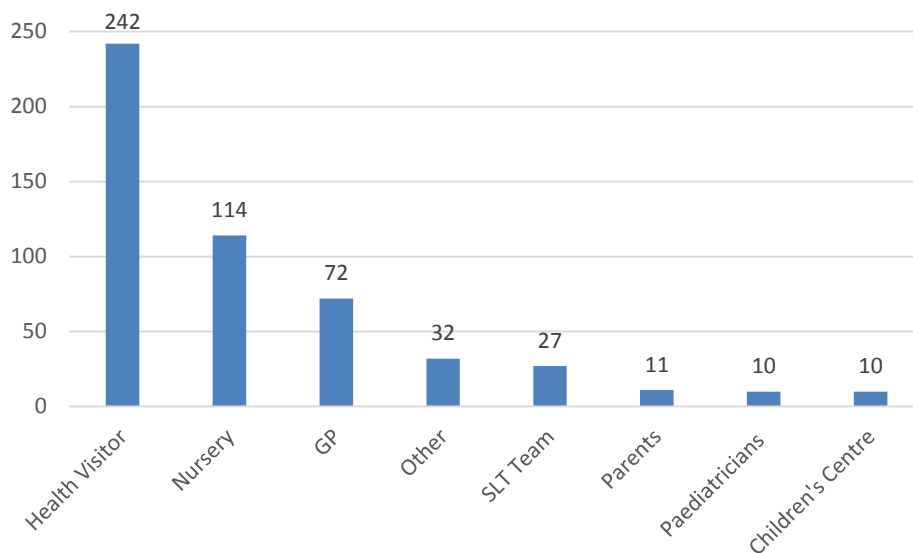


Source: Local Authority Special Educational Needs Dashboard, Westminster, 2016/17

### 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 (47% of referrals), followed by nursery schools (22% of referrals).

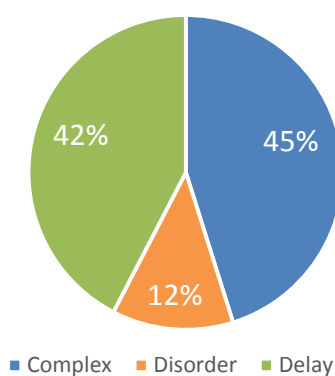
**Figure 6: Number of referrals by referrer in Westminster**



**Source: CLCH SLT 0-19 Service, referrals between April 2017 – February 2018 in Westminster**

Of the cases referred between September 2017 and February 2018, 45% of cases were for complex needs (1,861 children), 42% were due to developmental delay (1,747 children), and 12% were for a disorder (514 children).

**Figure 7: Percentage of cases by type**



**Source: CLCH SLT 0-19 Service, referrals between September 2017 – February 2018**

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

Since April 2017, only 72% of referrals for early years' speech and language therapy were seen for assessment within the target 8 weeks.

Only 74% 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	<b>72%</b> of referrals seen within 8 weeks
For treatment	12 weeks	<b>74%</b> receiving treatment within 12 weeks

Source: CLCH SLT 0-19 Service, referrals between April 2017 – February 2018

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## 4.2 School years

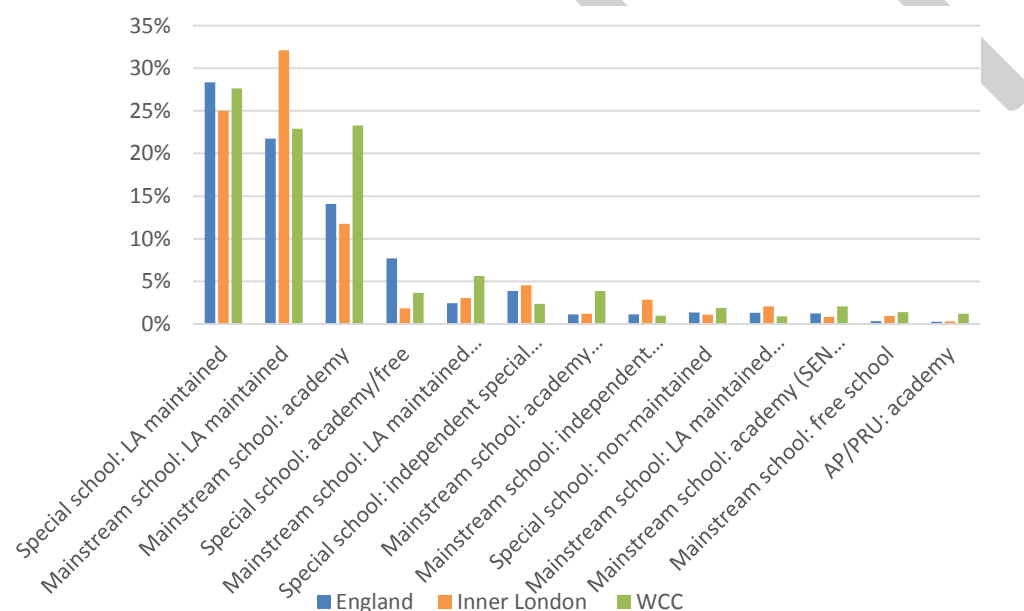
The best school or educational setting for a child depends on their needs. Most children with SEND, including those with Education, Health and Care Plans, will attend a mainstream school, college or university. Children with more specialist needs may benefit from a more specialist setting.

### 4.2.1 How many residents have SEND?

The number of children and young people for whom the local authority maintains a statement of SEN, or an EHC plan is 1,013, 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 special schools (28%), local authority maintained mainstream schools (23%) and mainstream school academies (23%).

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



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 Westminster there are:

- 14,825 pupils living in the borough, but 18,844 pupils attending schools maintained by the borough.<sup>9</sup>
  - 34% of pupils attending schools maintained by Westminster live in a different borough.
  - 15% of pupils who live in Westminster attend a school maintained by another borough.

<sup>9</sup> [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](#)



- Westminster is a net exporter of pupils to specialist provision in other Local Authority areas, with 63 pupils attending school outside of the authority, despite the special schools in the borough
- In 2015 it was found that 28% of pupils who go to school in the borough, attend a private school<sup>10</sup>. These pupils are out of scope of the school data (DfE).

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

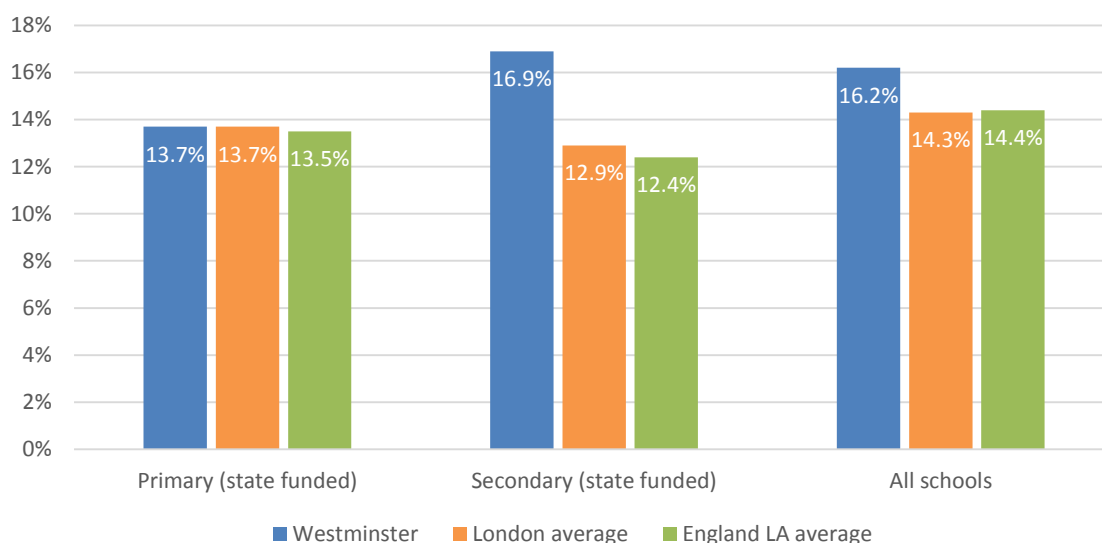
In 2017 an [External review of Westminster’s spend on children and young people with High Needs](#) was undertaken, which explains funding in detail, including pupils from outside the borough.

#### 4.2.2 How many pupils have SEND?

In Westminster 16.2% 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.<sup>11</sup>

- Westminster has a slightly higher 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 Westminster, January 2017**



Source: [DfE Special educational needs in England: table 14 & 15, January 2017](#)

#### 4.2.3 Trends over time

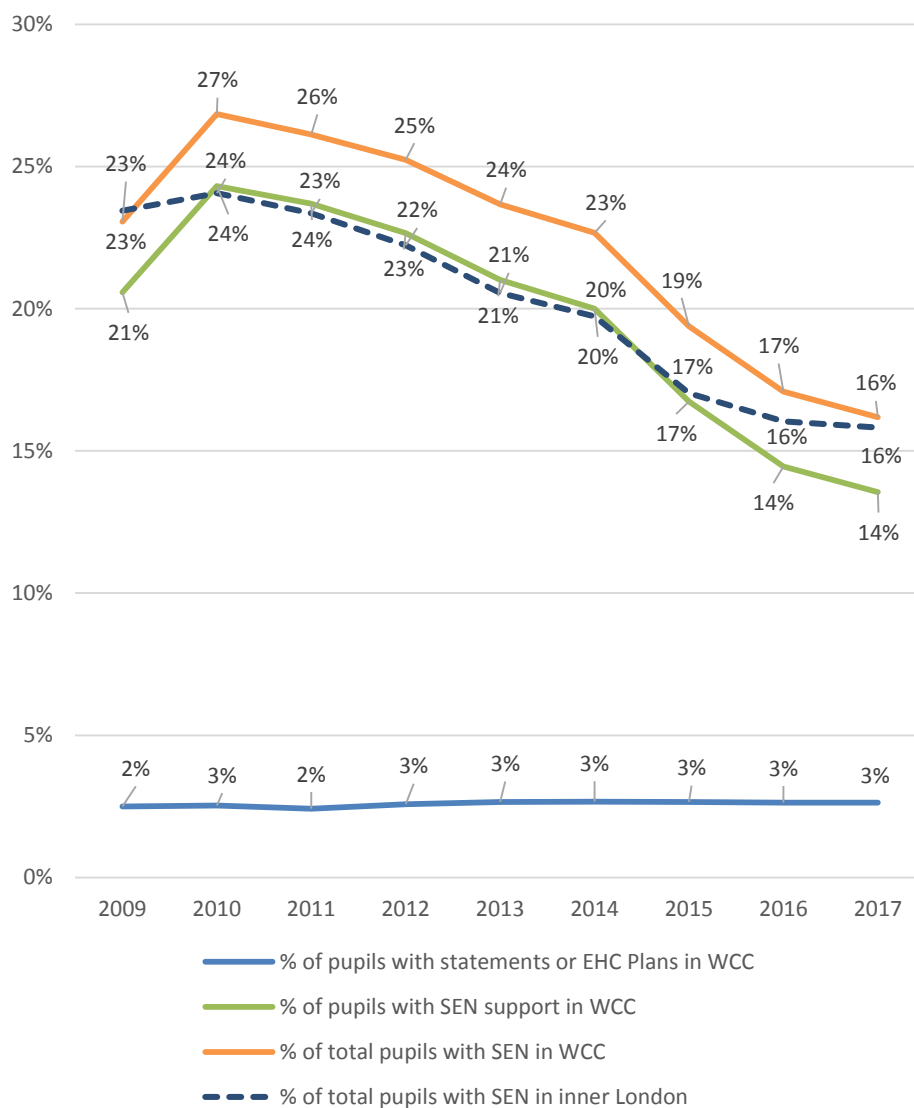
- The percentages of pupils with a statement or EHC plan in Westminster has been consistent with the inner London average since 2010.

<sup>10</sup> [GLA London Datastore: Schools and pupils, type, school, borough, 2015](#)

<sup>11</sup> NB these figures, are for pupils attending schools in Hammersmith and Fulham. They do not include children and young people for whom Hammersmith and Fulham is responsible but has placed out of borough

- The number of pupils with statements or EHC plans has increased since 2010
- The number of pupils with SEN support (without statements or plans) has decreased. This is as a result of a report by Ofsted in 2010 which criticised schools for identifying too many children as having SEN.

Figure 10: Percentage of pupils with a SEN 2010-2017 in Westminster

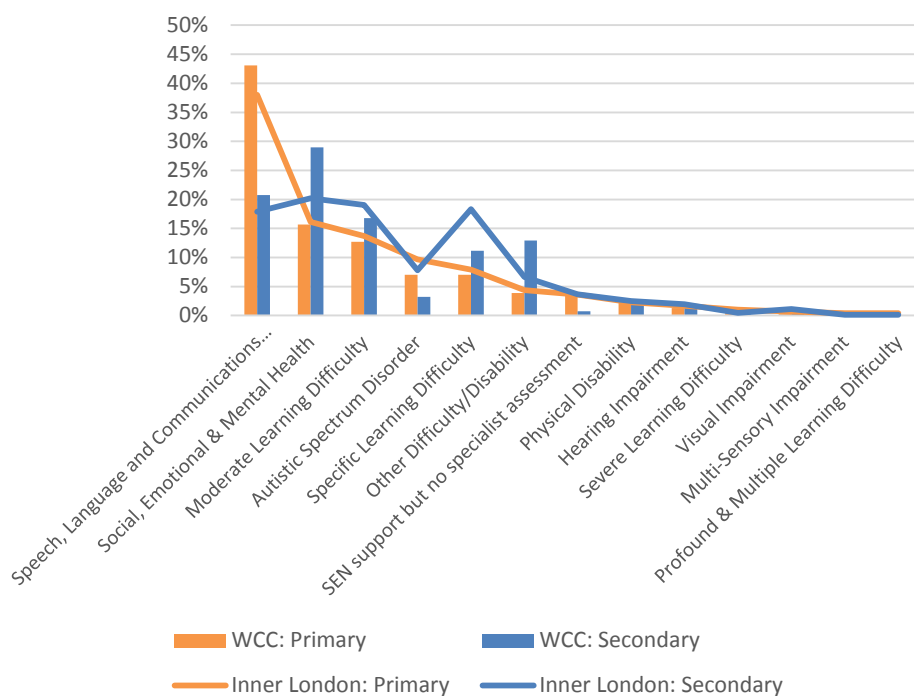


Source: [DfE statistics: special educational needs](#)

#### 4.2.4 Types of SEN needs locally

- **Nearly half (43%)** of state funded primary school pupils with SEN have **speech, language and communication** needs as their primary need
- **Nearly a third (29%)** of state-funded secondary school pupils with SEN have **social, emotional mental health needs**, nearly 10% more than the inner London average

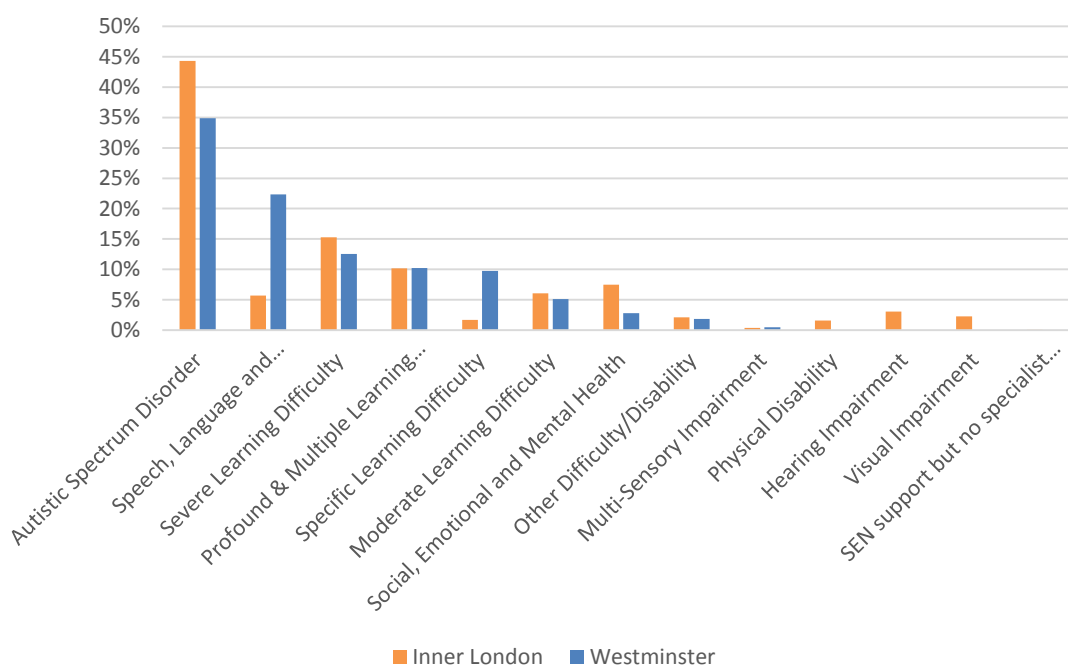
Figure 11: Percentage of state-funded primary and secondary school pupils in Westminster with SEN, by primary need



Source: [DfE Statistics: special educational needs 2017](#)

- Westminster has a higher proportion of pupils with speech, language and communication needs in special schools than inner London.

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



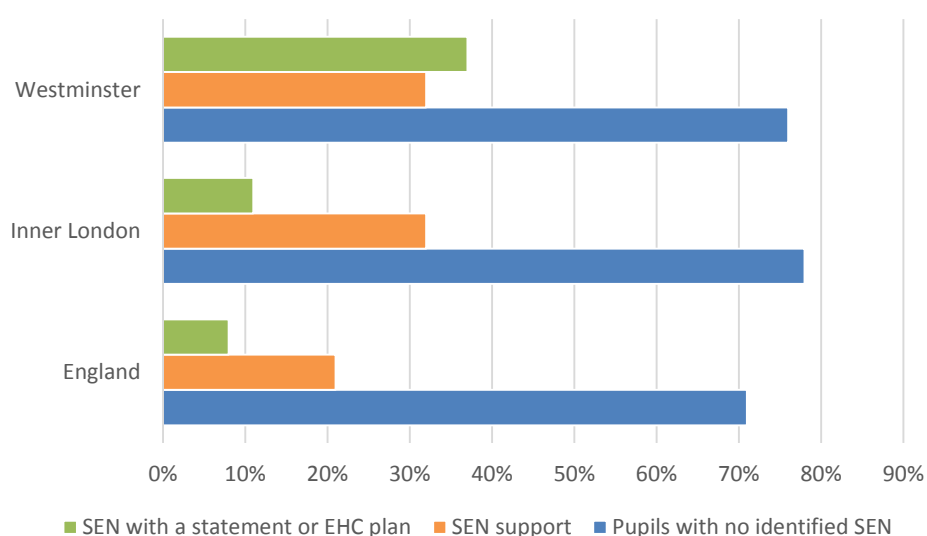
Source: [DfE Statistics: special educational needs 2017](#)

#### 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.

- Triple the percentage of pupils with a statement or EHC plan are reaching the expected standard in Westminster (30%) than the average across inner London (10%)
- However, there is a slightly lower percentage of pupils with SEN support reaching the expected standard than in comparison to inner London

**Figure 13: Percentage of pupils reaching the expected standard in reading, writing and mathematics at key stage 2 by SEN provision, 2017**

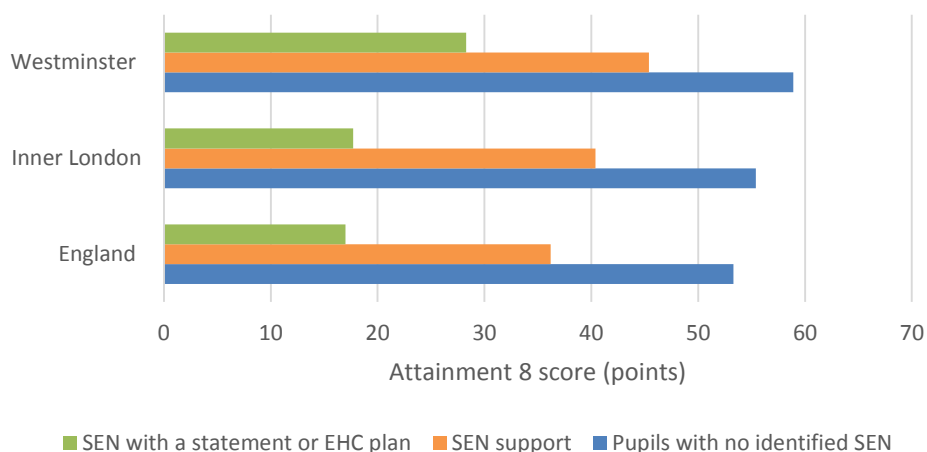


Source: [National curriculum assessments: key stage 2, 2017 \(revised\)](#), published 2018

**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 an EHC plan, statement or receiving SEN support have a higher average attainment 8 score in Westminster compared to inner London and England

Figure 14: Average Attainment 8 score per pupil at KS4, 2017/18



Source: DfE - GCSE and equivalent attainment by pupil characteristics, January 2018

- There is a higher percentage of **persistent absentees** amongst pupils with SEN in Westminster, inner London and England than amongst pupils with no identified SEN.
- Children with any form of SEN are significantly more likely to have at least one **fixed term exclusion**<sup>12</sup>

### 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 *et al.*, 2010). Fewer children with SEND are likely to report themselves as happy in the UK (59% compared with 67% of children without SEND) (Chamberlain *et al.*, 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<sup>13 14</sup>. 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.

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

<sup>12</sup> [DfE statistics SEN absences and exclusions](#)

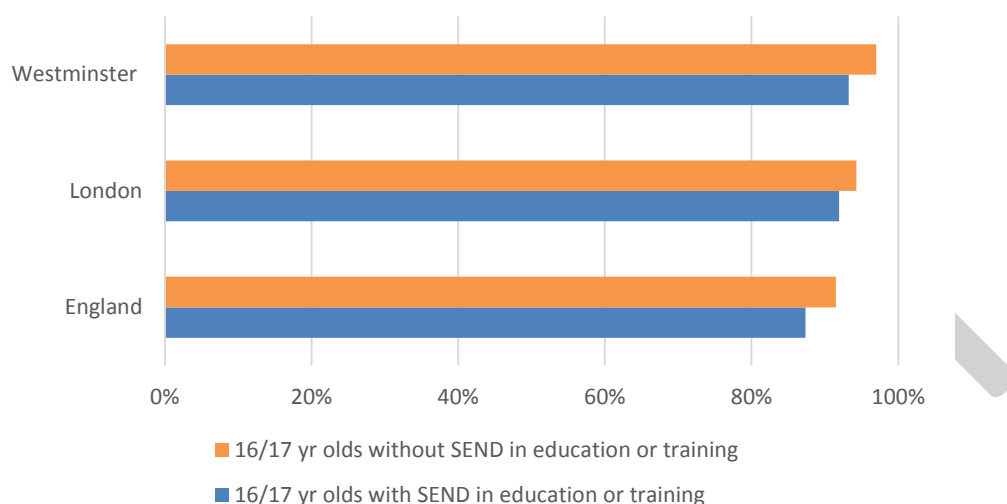
<sup>13</sup> Progression post-16 for learners with learning difficulties and/or disabilities, Ofsted survey, 2012

<sup>14</sup> [Moving forward?](#) How well the further education and skills sector is preparing young people with high needs for adult life, Ofsted, 2016

### 4.3.1 What do we know locally?

- As of June 2017, Westminster has slightly higher participation in education or training amongst the SEND cohort than the London and national average (93% of SEND cohort in education or training)

**Figure 15: Proportion of 16-17 year olds in Westminster (known to the LA) recorded in education and training by SEND, June 2017**



Source: [DfE Participation in Education and Training figures, 2017](#)

### 4.3.2 Post-16 Provision

The [Local Offer](#) details the support available for education, employment and training.

An external review of Westminster’s spend on children and young people with High Needs found that ‘Westminster is currently a low spender on post 16 specialist provision and is likely to experience further demands and pressures in this area. Provision and pathways will need to be more proactively planned.’<sup>15</sup>

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.

<sup>15</sup> Gray, P (2017) [A review of Westminster’s spend on children and young people with High Needs](#)

## 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<sup>16</sup>:

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.<sup>17</sup> 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 required is over and above what is available in the Local Offer, then the Local Authority will issue an EHC Plan.

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<sup>16</sup> [NHS Choices: Special Educational Needs](#)

<sup>17</sup> [NHS Choices: Special Educational Needs](#)

### EHC Plan assessments

In Westminster 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 35% of assessments in Westminster were conducted within the statutory time of 20 weeks, however, this has increased to 60% in 2017 (benchmarking data is not yet available for 2017).

Figure 16: Percentage of new EHC plans issued within 20 weeks in Westminster



Source: Statements of SEN and EHC plans, 2017, table 8, excluding exceptions

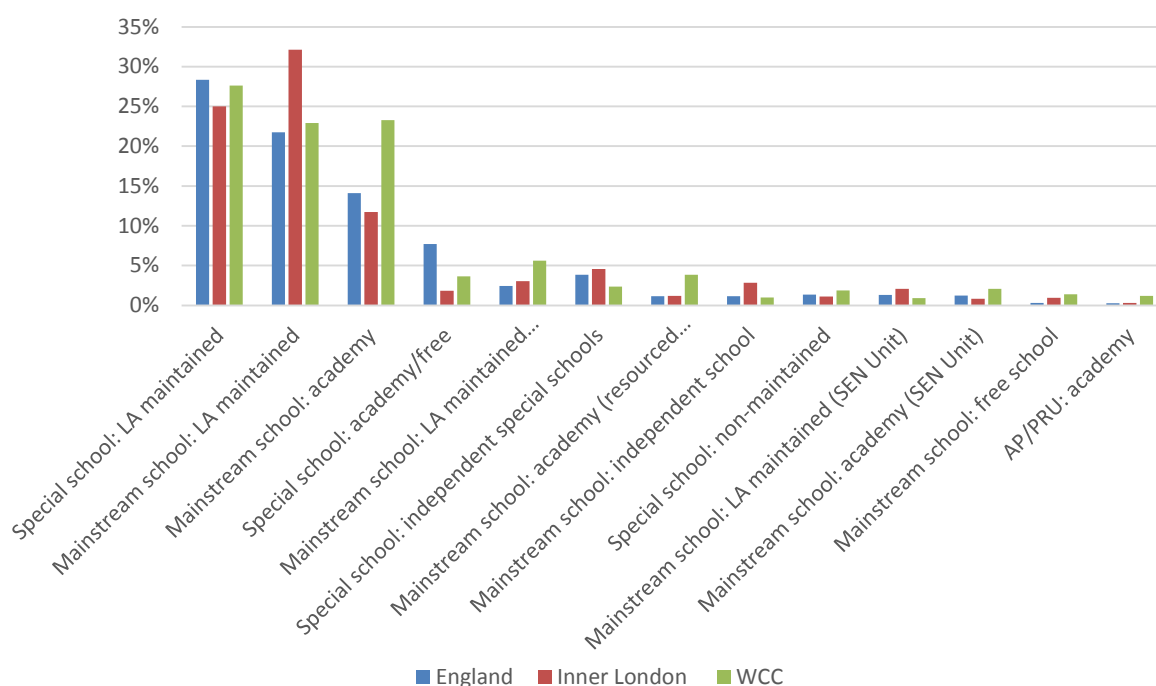
[Conducting an Education, Health and Care Needs Assessment flowchart](#)

#### 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 Westminster are educated in a special school, a mainstream school or an academy.



Figure 17: Placement of children and young people with a statement or EHC plan in Westminster



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.

In the centre and north of Westminster, the Child Development Service is provided by Imperial College Healthcare NHS Trust Child Development Service, and in the south of Westminster the service is provided by Chelsea and Westminster NHS Trust Cheyne Child Development Service.

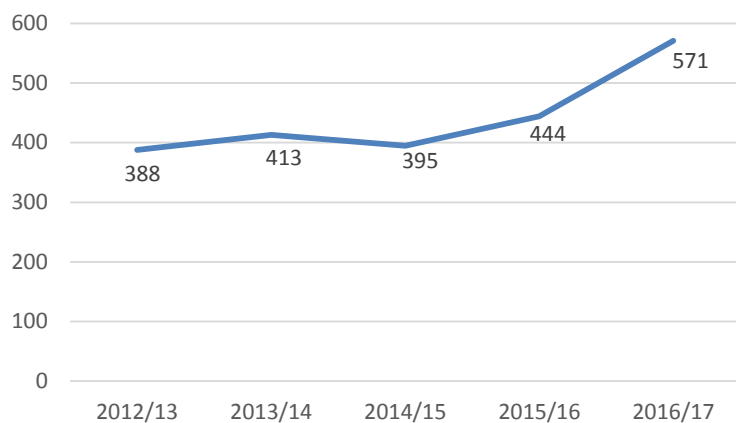
A Child Development Services offers comprehensive multidisciplinary and multi-agency services for children with neurodisabilities, communication disorders, and behavioural problems, as well as providing medical input into EHC Plans. The service assesses and treats children with developmental delay neurodisabilities, 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 Child Development Service in the centre and north of Westminster

Referrals to the Child Development service for the centre and north of Westminster have increased significantly (47%) since 2012/13. In particular, the Autism pathway has increased by 80% and the general developmental 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 the north of Kensington and Chelsea and north and centre of Westminster.

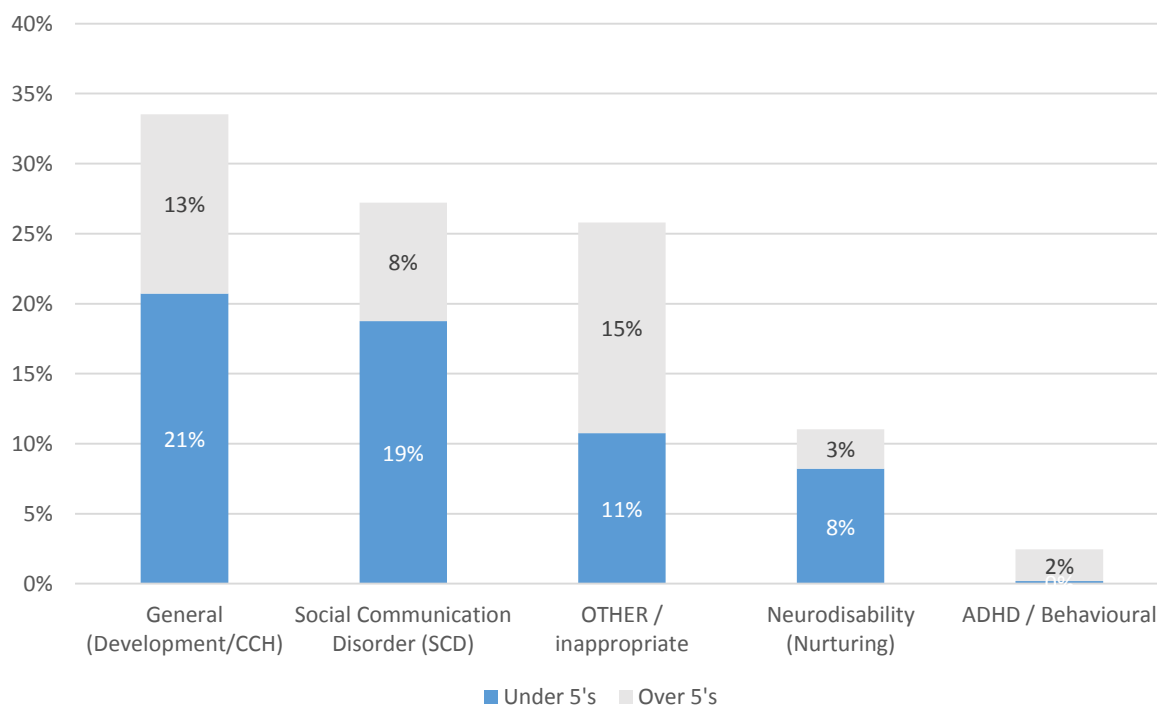
**Figure 18: New patients referred to the service**



Source: Imperial College Healthcare NHS Trust Neurodisability and child development service, November 2017

- General developmental delay has been the largest reason for referral 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**

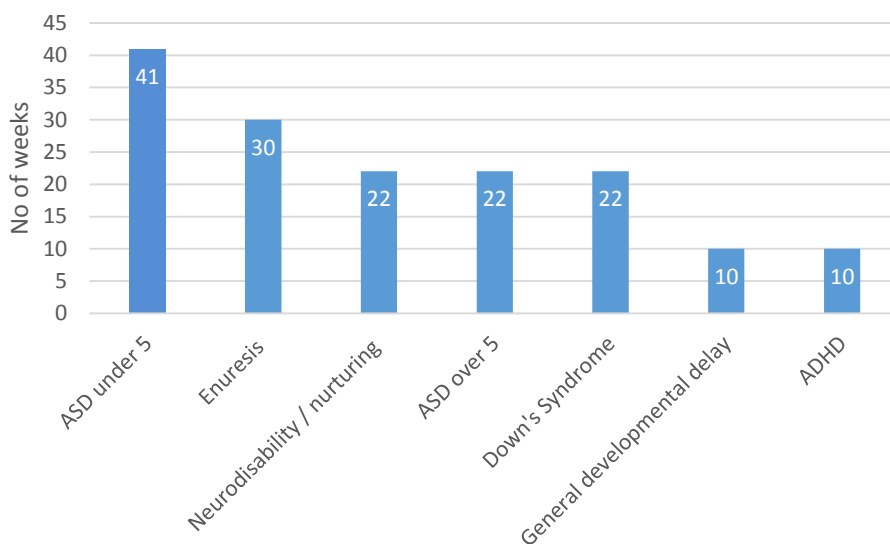


Source: Imperial NHS Trust Child Development Service, 2017/18, Q1-4 (Q4 predicted)

### 5.3.1 Waiting time in centre and north Westminster

NICE guidelines state that an autism diagnostic assessment should start within three months of the referral to the autism team<sup>18</sup>. 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



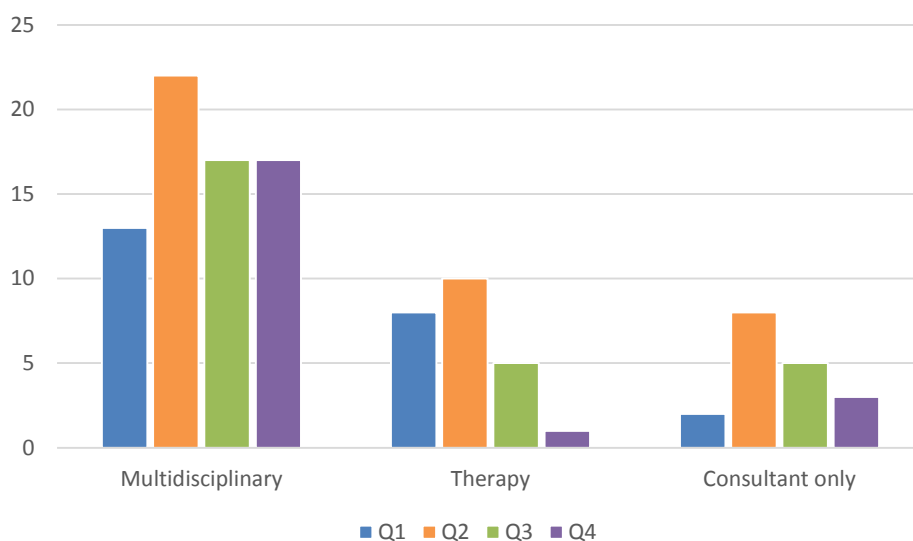
Source: CLCH Imperial NHS Trust Child Development Service, November 2017

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

- There were 137 referrals to the Child Development Service in 2017/18
- Most referrals in the south of Westminster require appointments with a multi-disciplinary team, which requires the most resource.

<sup>18</sup> [National Institute for Health and Care Excellence: Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#)

Figure 21: Referrals to the Child Development Service by appointment type

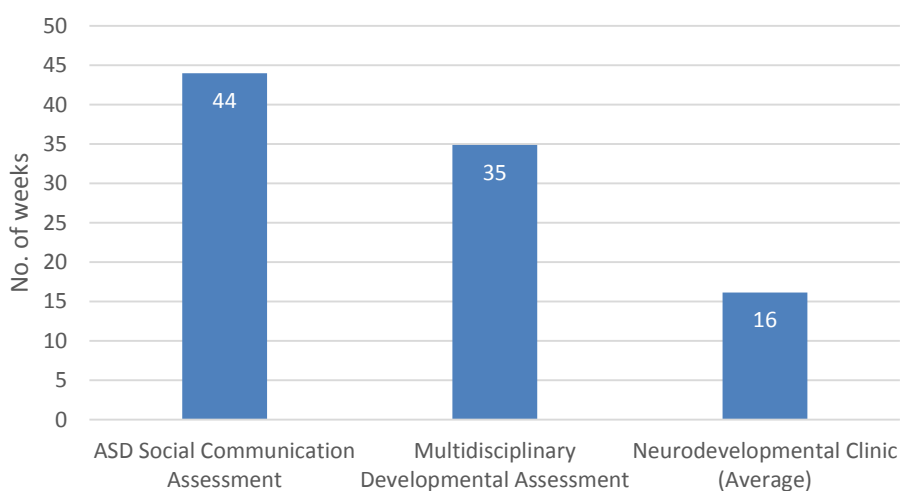


Source: Chelsea and Westminster Hospital NHS Trust, Child Development Service Q1-4, 2017/18

#### 5.4.1 Waiting time in the south of Westminster

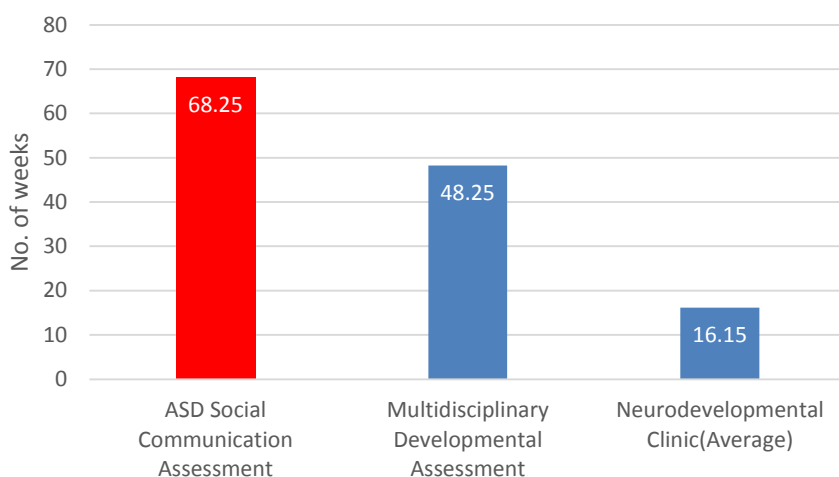
- Average waiting times for referral to diagnosis of ASD for 4.5 year olds and older was longer than a year in 2017/18.
- NB. This is the average waiting for the service, which includes referrals from parts of Westminster, Kensington and Chelsea and Hammersmith & Fulham
- 

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

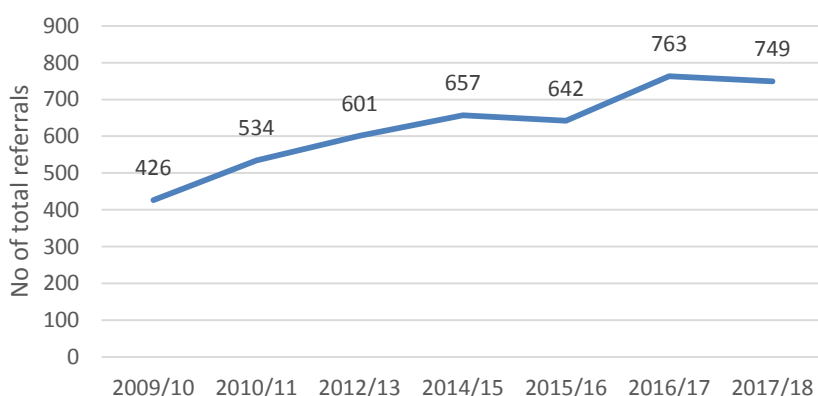


Source: Chelsea and Westminster NHS Trust Child Development Service, 2017/18

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 2009/10 to 2017/18



Source: Chelsea and Westminster NHS Trust Child Development Service, April 2018

## 6 Conditions 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 (SLCN)

### 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<sup>19</sup>.

‘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<sup>20</sup>

### 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<sup>21</sup>.

Language skills are linked to academic success and positive self esteem<sup>22</sup>. 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<sup>23</sup>

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. <sup>24</sup>.

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<sup>19</sup> (I CAN, 2006)

<sup>20</sup> [I CAN](#), accessed 2017

<sup>21</sup> (Lindsay & Dockrell, 2012)

<sup>22</sup> (I CAN, 2006)

<sup>23</sup> (Public Health England & the UCL Institute of Health Equity, 2014)

<sup>24</sup> (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.

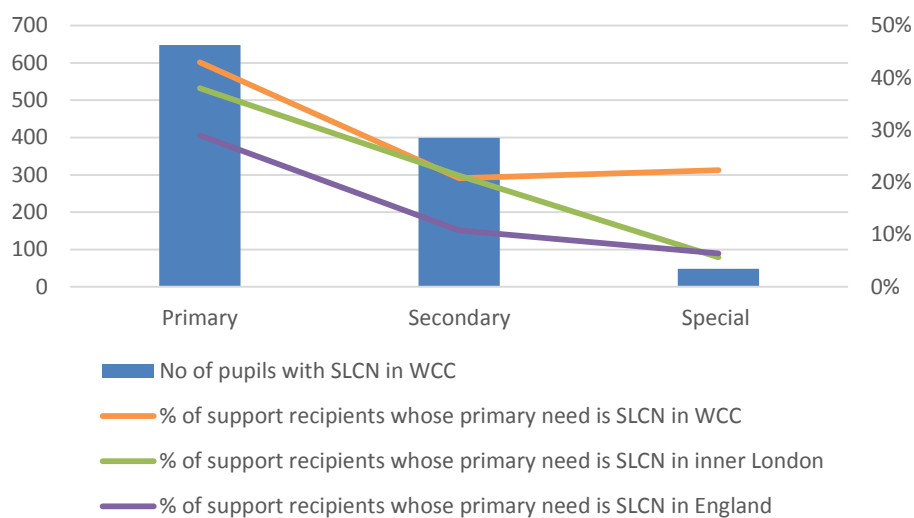
### ***Prevalence by demography***

- **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. This cohort makes up 14.3% of the general school population and 16.1/14/1% of the SEN/statement of EHCP population.
- **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 620 early years' referrals to the SLT team in 2017/18 (including Q4 predictions). Please see Early Years section above for more information.
- In **Westminster**, there are **1,095 pupils receiving SLCN support** (34% of all pupils with SEN and 3% of all pupils) and it is the most common reason for SEN support among primary school pupils
- Westminster follows the trend as seen in inner London and England, with a smaller proportion 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.

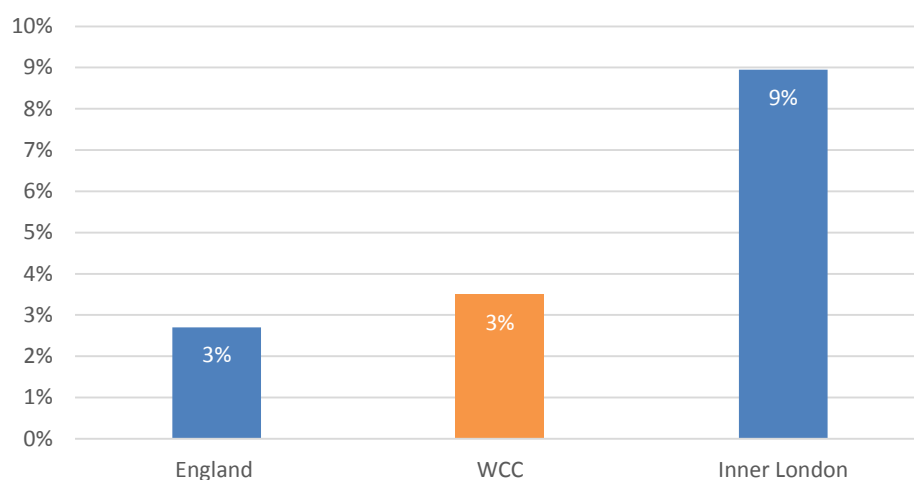
Figure 25: Numbers of pupils with SLCN and percentages of pupils with SEN that have SLCN as their primary need



Source: [DfE Special educational needs, state funded schools, number of pupils with SEN by primary type of need: SLCN](#)

- Westminster has a lower percentage of children overall with SLCN than inner London, despite SLCN being the most common primary need in primary school (43%) and the second most common need in special schools.

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



Source: [DfE Special educational needs, state funded schools, number of pupils with SEN by primary type of need: SLCN](#)

**True prevalence may be much higher.** The Department of Health’s [guidance to Health & Wellbeing Boards](#) 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<sup>25</sup>.

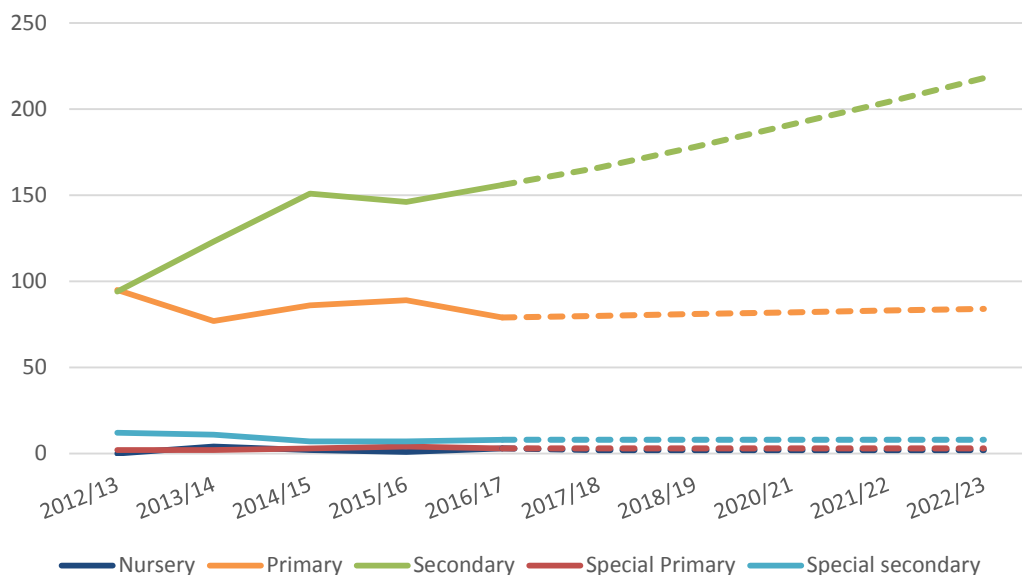
<sup>25</sup> (I CAN, 2011)



### 7.3.1 Future trends

Based on 2013-2017 trends, it is predicted that there could be 23% increase of pupils with SLCN that go to school *and* live in Westminster between 2017 and 2023. *This figure excludes pupils who attend school in Westminster but live in another borough.*

**Figure 27: Number and projected number of pupils that go to school *and* live in Westminster with SLCN**



Source: GLA pupil roll and school census 2017, NB. dashed lines are projections

The **Joint Commissioning plan 2018/19** has identified speech, language and communication needs as a priority:

The challenge	Proposed actions
<p>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.</p>	<ol style="list-style-type: none"> <li>1. New service model implemented by CLCH, which manages demand and is more cost effective</li> <li>2. 0-25 graduated model in place by October 2019</li> <li>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.</li> </ol>

## 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. 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<sup>26</sup> 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, a final report by Jean Gross CBE, Government's Communication Champion for children and young people, responsible for promoting the importance of good language skills published a two-year follow-up<sup>27</sup> 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

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<sup>26</sup> (I CAN, 2008)

<sup>27</sup> (Gross, 2011)

- 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'<sup>28</sup> 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.

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<sup>28</sup> (Gascoigne, 2012)

### **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.

### ***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.

## 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.<sup>29</sup> Children and young people who experience these difficulties may have a medical mental health diagnosis and may have special educational needs<sup>30</sup>.

The SEND Code of Practice 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.<sup>31</sup>

### 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<sup>32</sup>
- 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<sup>33</sup>

### 8.3 What do we know locally?

- Social, emotional and mental health difficulties are the second most common reason a pupil with SEND might be receiving support in Westminster. Of the pupils receiving support for SEN, Westminster has a lower proportion receiving support for SEMH in special schools compared to inner London and England.

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<sup>29</sup> [Royal College of Speech and Language Therapists](#)

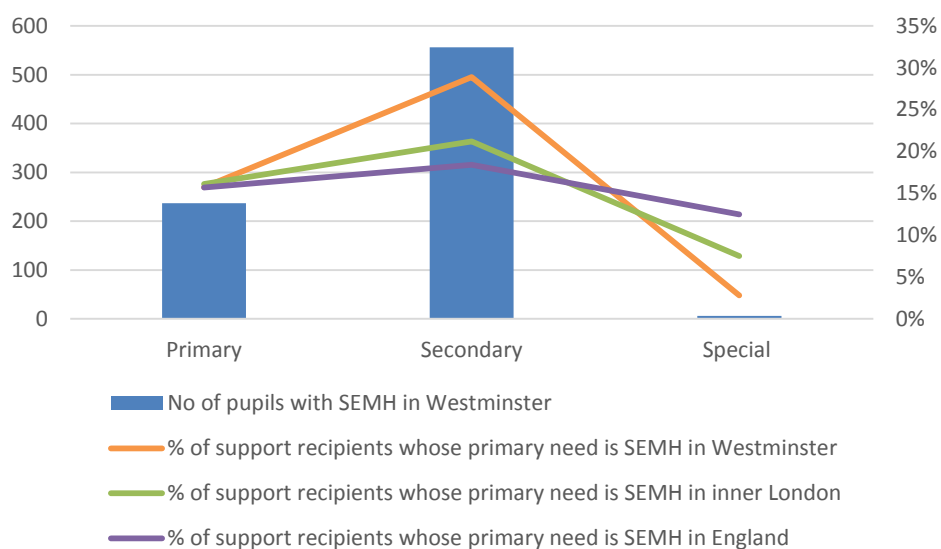
<sup>30</sup> [Royal College of Speech and Language Therapists](#)

<sup>31</sup> [SEN Code of Practice](#)

<sup>32</sup> [Department of Education, 2016](#)

<sup>33</sup> [NICE, 2008](#)

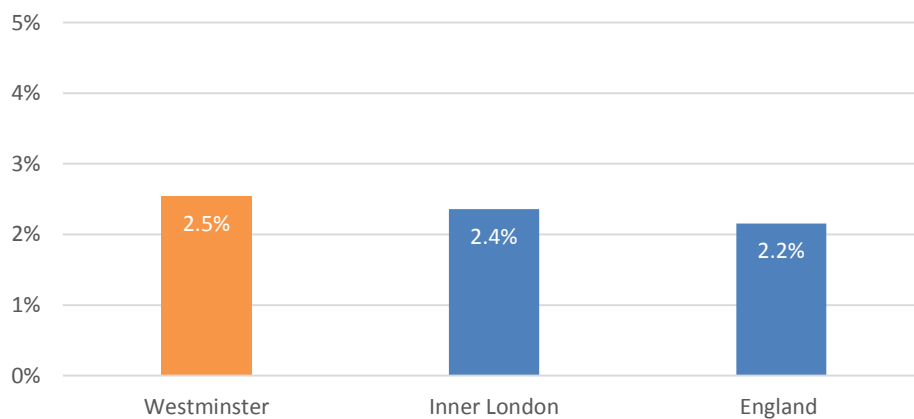
Figure 28: Numbers of pupils with SEMH and percentages of support recipients whose primary need is SEMH



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

- Westminster has a similar proportion of all pupils receiving support for social, emotional and mental health, as the inner London average and England average

Figure 29: Percentage of all pupils with social, emotional mental health

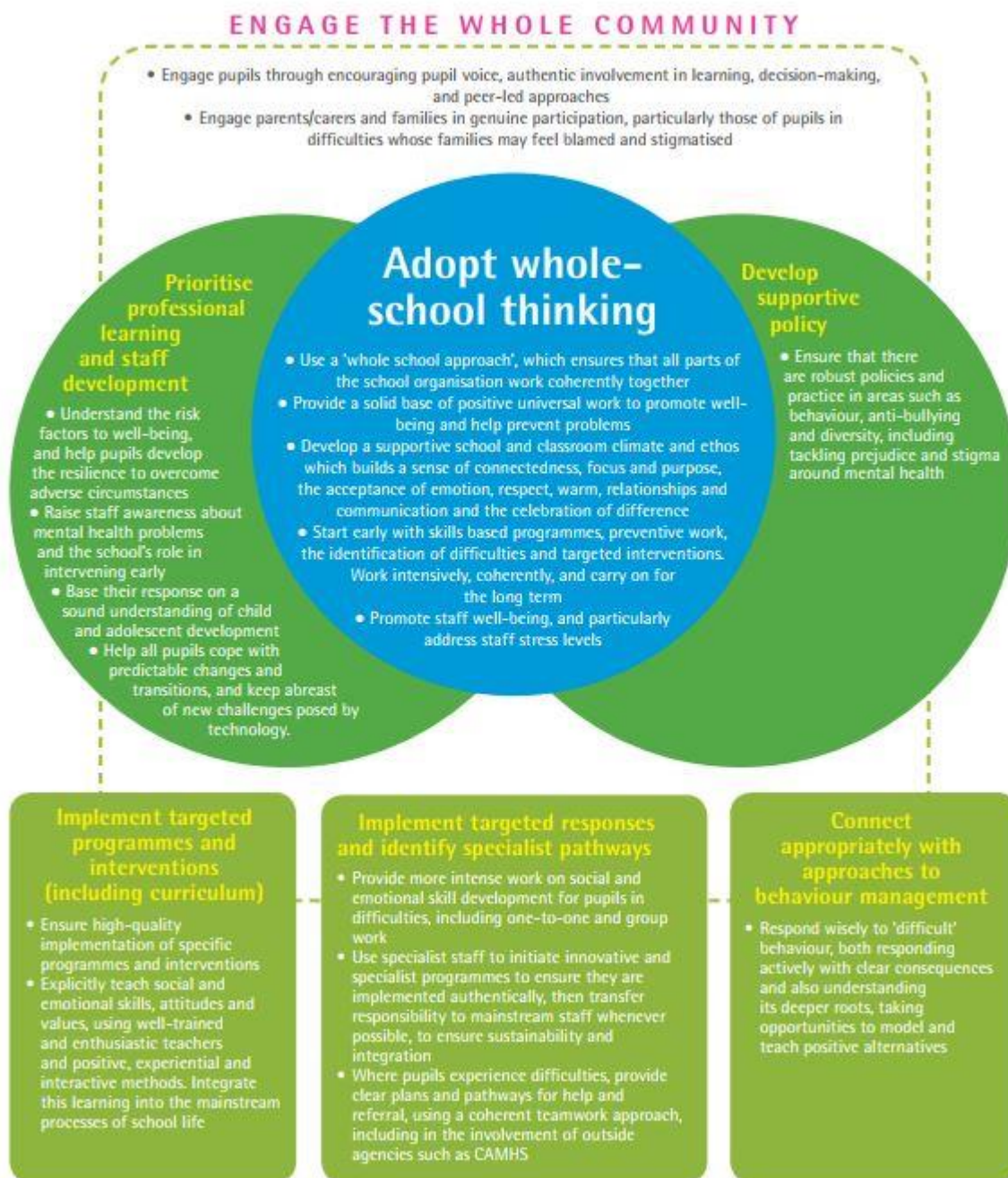


Source: DfE Special educational needs, state funded primary, secondary and special schools, number of pupils with SEN by primary type of need: SEMH, 2017

### 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





**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'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](#)



## 9 Specific Learning Difficulties

### 9.1 Background

Learning difficulties (called specific learning difficulties or SpLD in an educational context) are conditions that 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?

The British Dyslexia Association [estimates](#) that 15% of the population has at least one SpLD.

- 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 ratio 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<sup>34</sup>.
- 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<sup>35</sup>.
- 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<sup>36</sup>

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<sup>34</sup> (Eissa, 2010)

<sup>35</sup> (Public Health England & the UCL Institute of Health Equity, 2014)

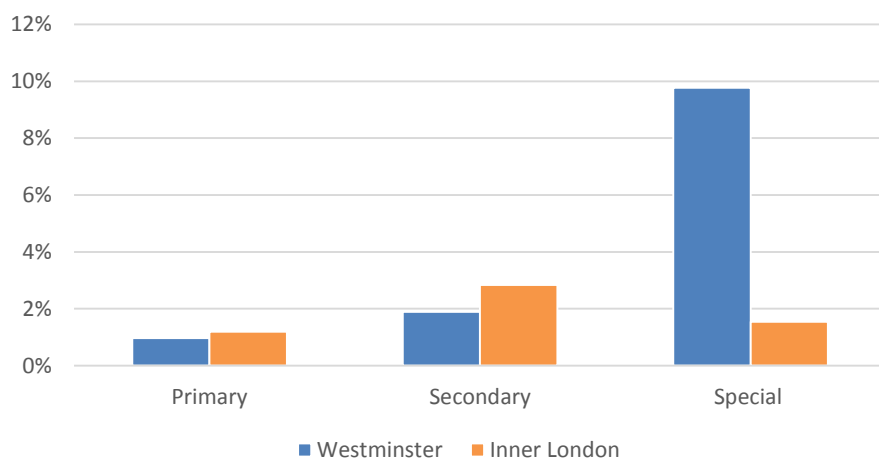
<sup>36</sup> (Nigg J. , 2012)

- 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<sup>37</sup>.

### 9.3 What do we know locally?

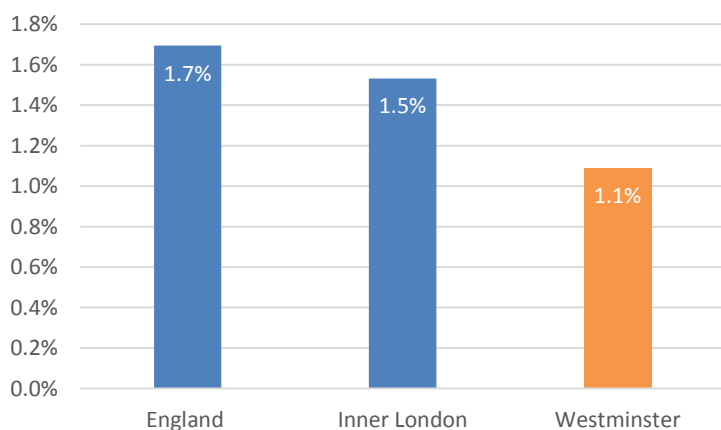
341 pupils in Westminster are receiving SEN support primarily for specific learning difficulties, as of January 2017. (1% of primary pupils, 1.9% of secondary pupils, and 9.8% of special school pupils). Westminster has a higher than average percentage of special school pupils with specific learning difficulty as their primary SEN need.

Figure 30: Percentage of all pupils in each type of school with a specific learning difficulty



Sources: DfE - [Special Educational Needs](#) and [School and pupil numbers, January 2017](#)

Figure 31: Percentages of all pupils who have a specific learning difficulty



Source: DfE - [Special educational needs in England, January 2017](#), [Schools, pupils and their characteristics: January 2017](#)

<sup>37</sup> (Caçola, 2016)

### 9.4 What works?

A 2012 report<sup>38</sup> 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*<sup>39</sup> 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<sup>40</sup> 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

<sup>38</sup> (Dyslexia Action, 2012)

<sup>39</sup> (Dyslexia Action, 2013)

<sup>40</sup> (Brooks, 2016)

	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<sup>41</sup>. Conditions such as epilepsy and cerebral palsy are also common.

Health outcomes determined by other factors, which have a lifelong impact, are also affected. 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<sup>42</sup>.

### 10.2 What do we know nationally?

- Public Health England estimates that 2% of people in England have a learning disability<sup>43</sup>.
- 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 (see Table 1 below).

#### 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.
- **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 2: 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
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<sup>41</sup> (Prasher & Routhu, 2016)

<sup>42</sup> (Public Health England, 2015)

<sup>43</sup> (Public Health England, 2015)

SEN support	18.6%	23.2%	33.3%	16.1%
Statement of SEN or EHC Plan	11.6%	18.1%	24.4%	14.1%

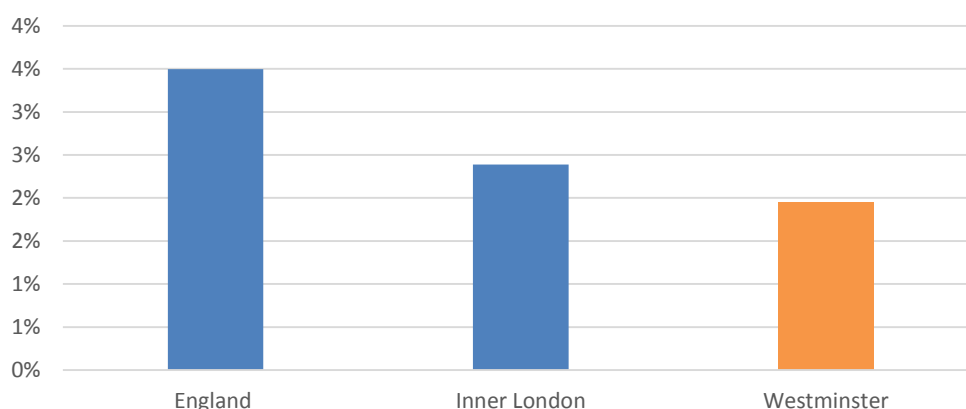
Source: DfE Statistics: [Special Educational Needs](#)

- 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 **114 children and young people** aged 0-25 with learning disabilities known to GPs within the Central London clinical commissioning group (November 2017), 0.2% of the CCG 0-25 population.
- **Gender:** 68% of those known to GPs are male and 32% are female
- **Social care:**
  - Learning disabilities is the third highest proportion of social care cases in Westminster amongst children in need aged 0-17.
  - Nearly half (48%) of social care cases for people aged 18-25 are for learning disabilities support
- **Co-occurring conditions:** In Westminster Learning disabilities co-occurs with mental health disorders (nearly all in Westminster have a co-occurring mental health disorder), autism and sensory impairments.
- In 2014/15 Westminster had the third lowest recorded prevalence for learning disabilities in London.
- In 2017 Westminster has similar percentages of pupils with learning disabilities as inner London, both of which have a smaller proportion than England overall.

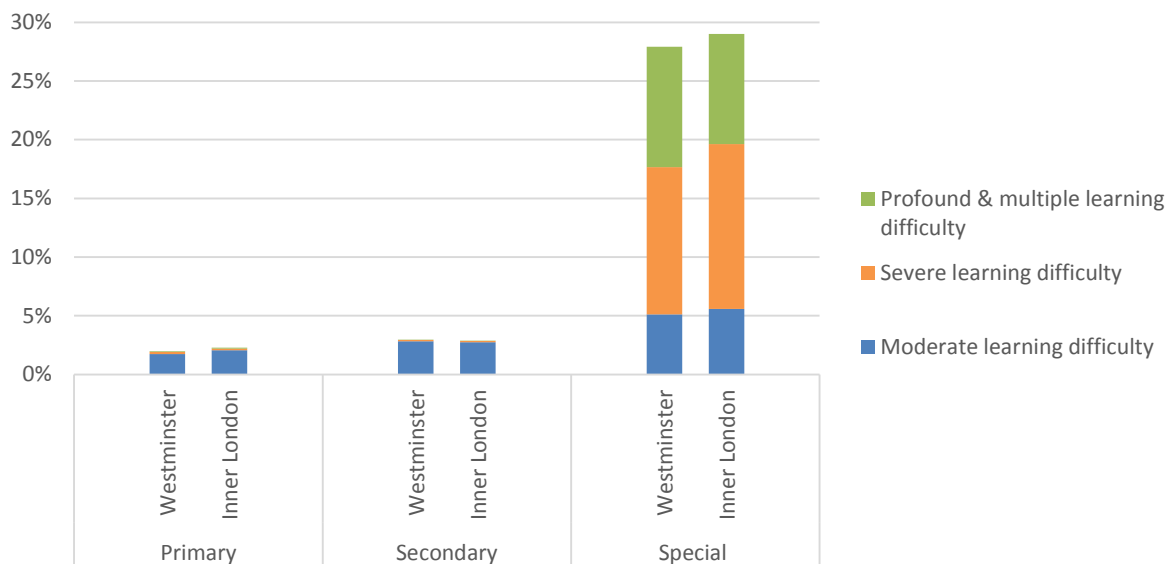
Figure 32: Percentage of all pupils that have learning disabilities



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

Figure 33: 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](#)

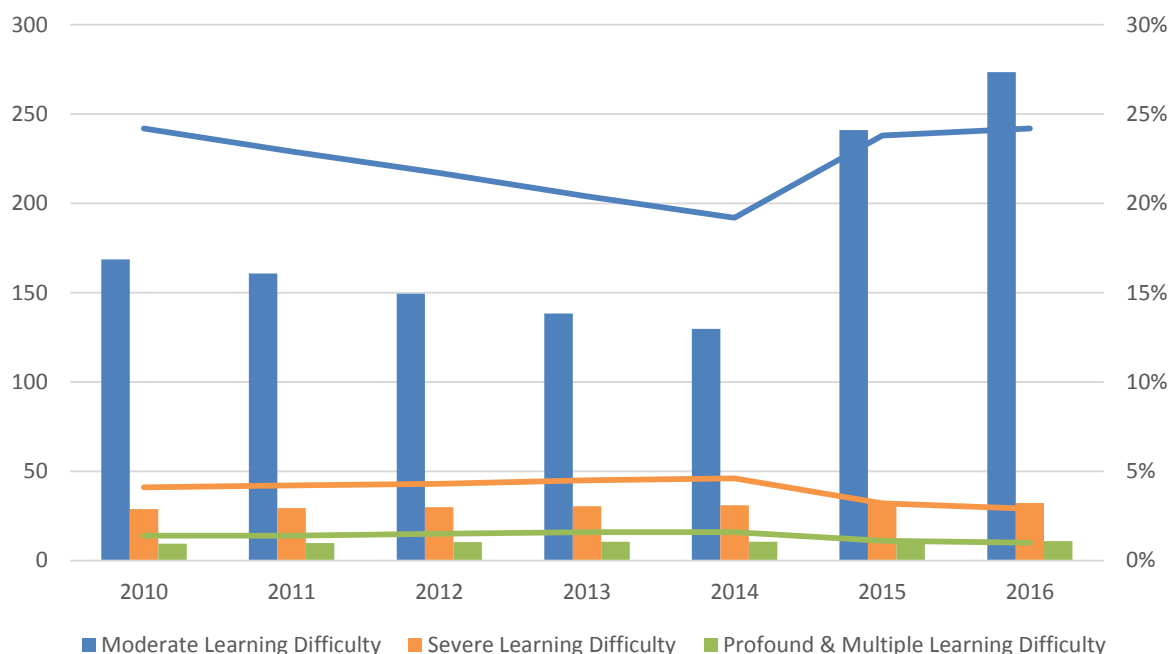
### Trends

Since 2015, children receiving support for SEN are also counted in these statistics; previously, only children with 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%. 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 34: 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. The full guidelines can be viewed online<sup>44</sup>. 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 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

For further information of the six good practice initiatives identified please visit - [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/261896/Learning Disabilities Good Practice Project November 2013 .pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/261896/Learning_Disabilities_Good_Practice_Project_November_2013_.pdf)

<sup>44</sup> NICE (2015) *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges* <https://www.nice.org.uk/Guidance/NG11>

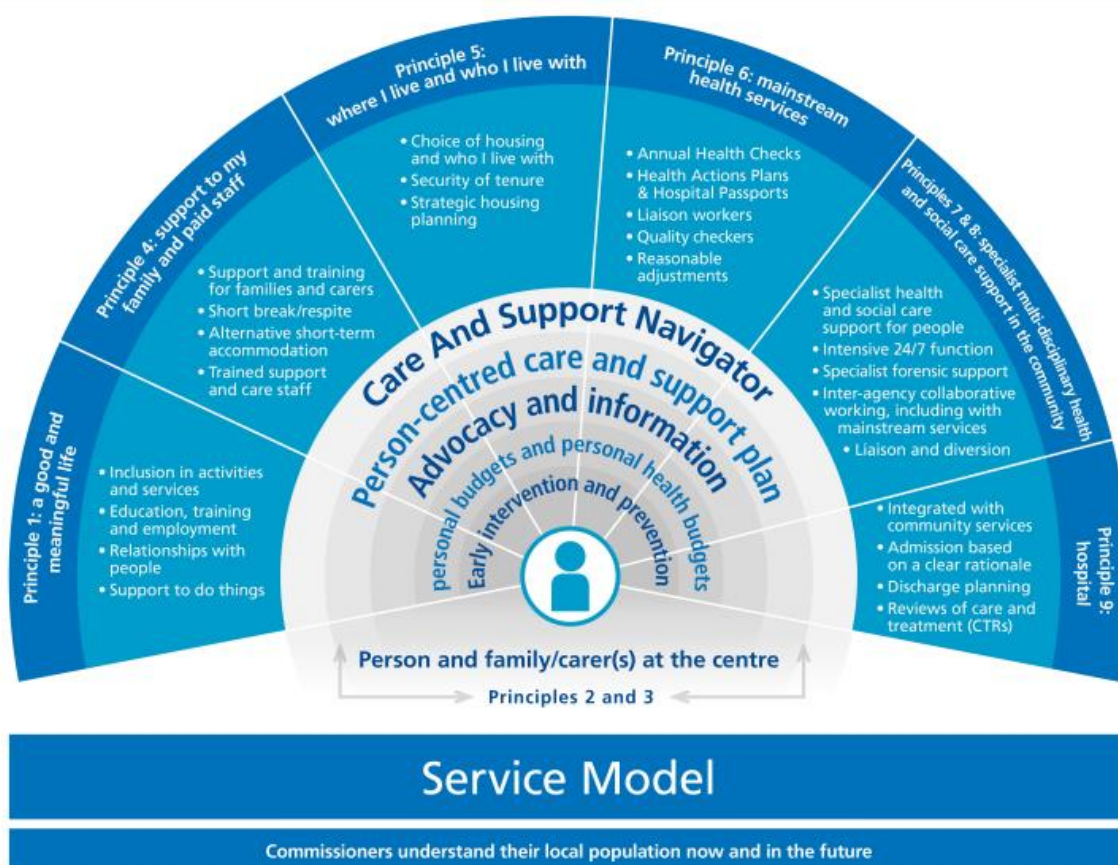


### Service models

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 35: 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.’ 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 and 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.<sup>45</sup>
- 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.<sup>46</sup>

### 11.3 What do we know locally?

- There are **559** children and young people aged 0-25 registered with their GP with autism, equivalent of 1% of the CCG 0-25 population, however this is said to be an undercount
- Gender: 78% male and 22% 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:

- 106 in primary school (7% of children with SEN, slightly below the inner London average of 9.7%)
- 62 in secondary school (3.2% of children with SEN, slightly below the inner London average 6.9%)
- 75 in special primary and secondary schools (34.9% of children with SEN, slightly higher than the inner London average at 44.3%)

Sources: DfE Statistics: [Special Educational Needs](#)

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<sup>45</sup> (Schieve, et al., 2012)

<sup>46</sup> (Office for National Statistics, 2009)

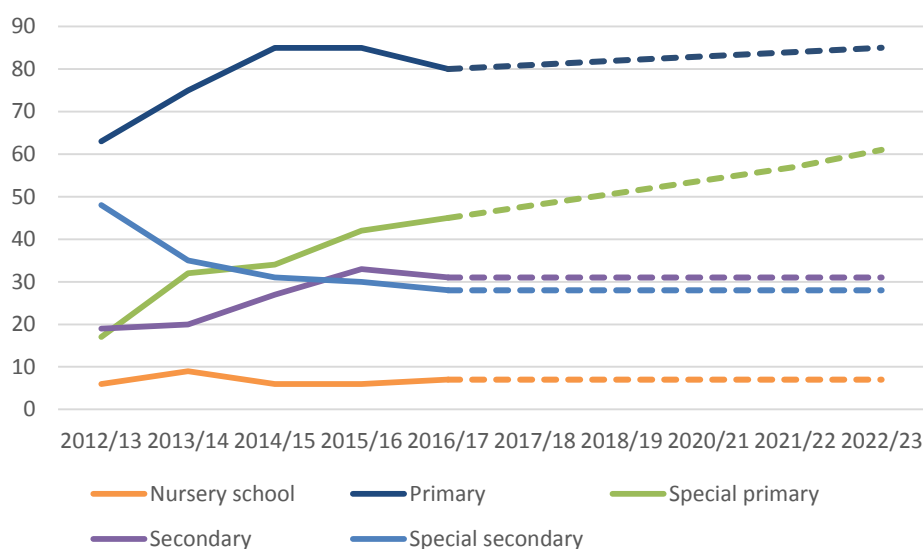
### 11.3.1 Future trends

From 2008-2012 there were 50% more children with ASD in London, but in the three boroughs there were 91% more<sup>47</sup>. 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 a special 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 36: Projected increase in numbers of children in who go to school *and* live in Westminster



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. 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. The full guidelines can be viewed online<sup>48</sup>.

<sup>47</sup> (Department of Education, 2012)

<sup>48</sup> [NICE Autism spectrum disorder in under 19s: support and management](#)

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 of 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 year's 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.<sup>49</sup>

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 –while 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 ([Equality Act 2010](#)).

A 2016 report by The Council for Disabled Children<sup>50</sup> 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.<sup>51</sup>

### 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.

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<sup>49</sup> [Understanding the needs of disabled children with complex needs or life-limiting conditions](#)

What can we learn from national data? Anne Pinney, Council for Disabled Children, 2016

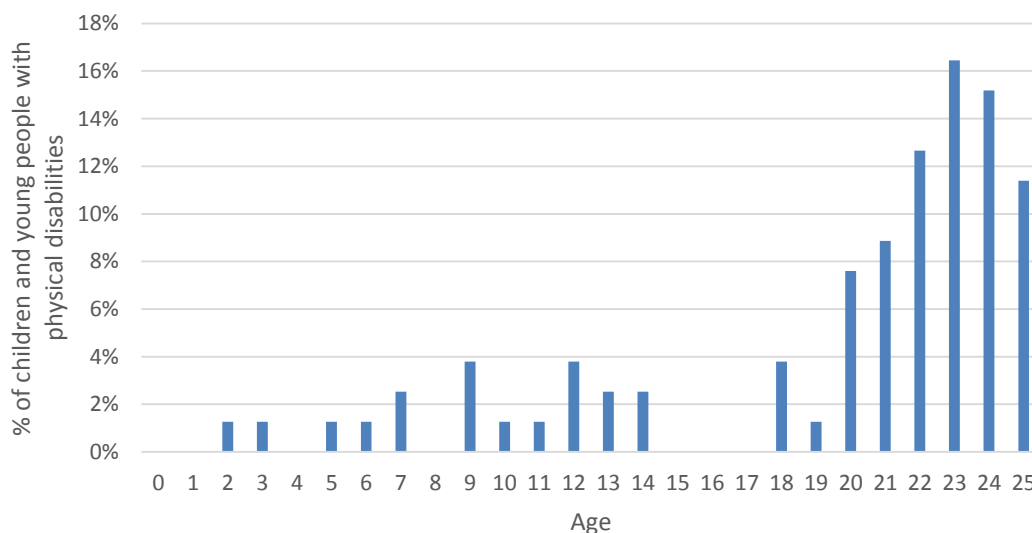
<sup>50</sup> Council for disabled children report

<sup>51</sup> .(From [council for disabled children](#)) g. JRF (1995) The needs of disabled children and their families; Audit Commission (2003) Services for disabled children; CQC (2012) Healthcare for disabled children and young people

### 12.3 What do we know locally?

- There are **76 children and young people** aged 0-25 registered with a GP in the Central CCG boundary with physical disabilities, 0.2% of the CCG 0-25 population (November 2017)
- **Gender:** 47% male and 53% female
- **Co-occurring conditions:** 12% have a co-occurring condition of mental health, mainly amongst the older cohort

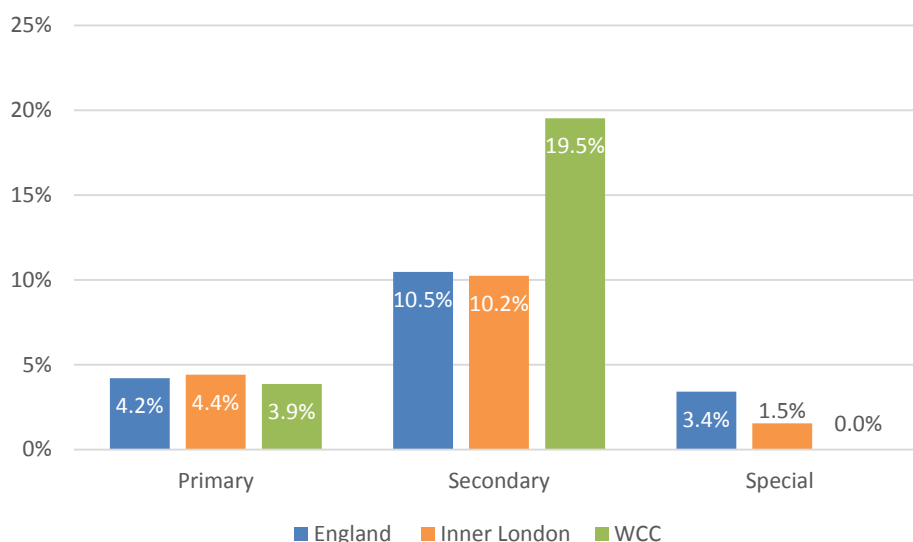
Figure 37: Percentage of children and young people with physical disabilities by age



Source: System One and QOF data, Westminster CCG, as at November 2017

- As of January 2017 3.9% of all primary school pupils with SEN, 19.5% of secondary pupils with SEN, and 0% of special school pupils had physical disabilities as their primary need in Westminster

Figure 38: 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

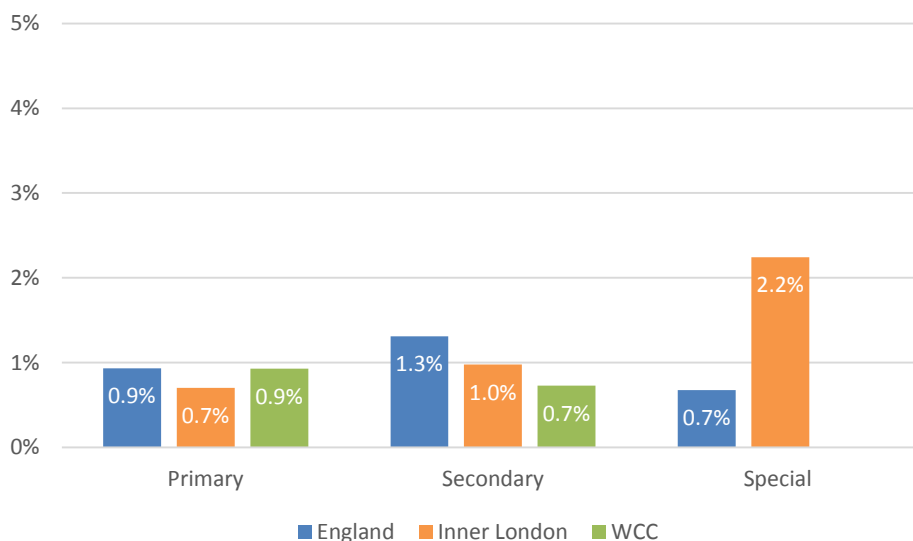
Visual loss or impairment in childhood or adolescence can significantly impair their physical, emotional and social development. Around half the children receiving support from visual impairment services may have additional disabilities, and this proportion is likely to be even higher for children with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

In a study by Rahi and Cable, 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 where inter-cousin marriages are common, autosomal recessive disorders are found.

- There are 89 children and young people aged 0-25 with a visual impairment known to their GP in the CCG boundary, 0.2% of the CCG 0-25 population
- Majority of cases (48%) are for impaired vision, with 4% of cases for complete blindness
- Gender is a factor: 62% are male and 38% are female
- 1% of social care cases of the Children’s Disability Team are for visual impairment
- 0.9% of primary pupils with SEN, 0.7% of secondary pupils with SEN, and 0% of special school pupils with SEN have visual impairment as their primary need

Figure 39: Percentage of all pupils with SEN, whose primary need is visual impairment



Source: DfE Special educational needs in England: January 2017



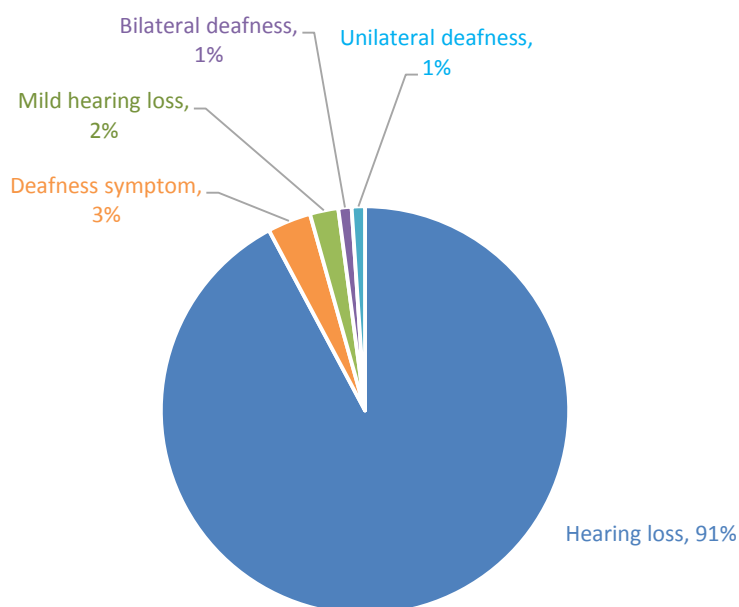
### 12.4.2 Hearing impairment

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 673 children and young people aged 0-25 with a hearing impairment known to their GP within the Central CCG boundary, 1% of the CCG 0-25 population
- The picture is similar for male and female, with the gender split 50/50
- 2% 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 (91%), with small percentages with bilateral and unilateral deafness.

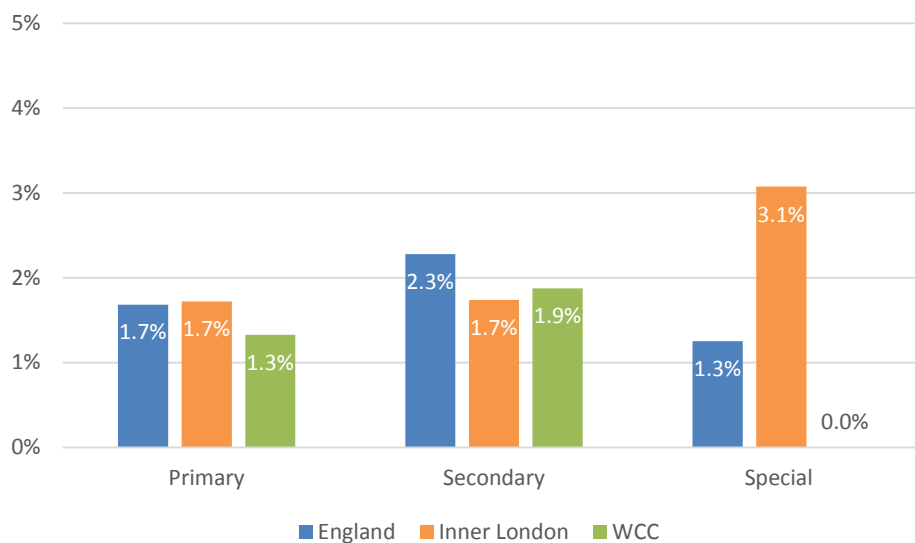
Figure 40: Proportion of children and young people with hearing impairment by level of impairment



Source: System One and QOF data, Central CCG, as at November 2017

- 1.3% of primary pupils with SEN, 1.9% of secondary pupils with SEN, and 0% of special school pupils with SEN have hearing impairment as their primary need

Figure 41: Percentage of all pupils with SEN, whose primary need is hearing impairment



Source: DfE Special educational needs in England: January 2017

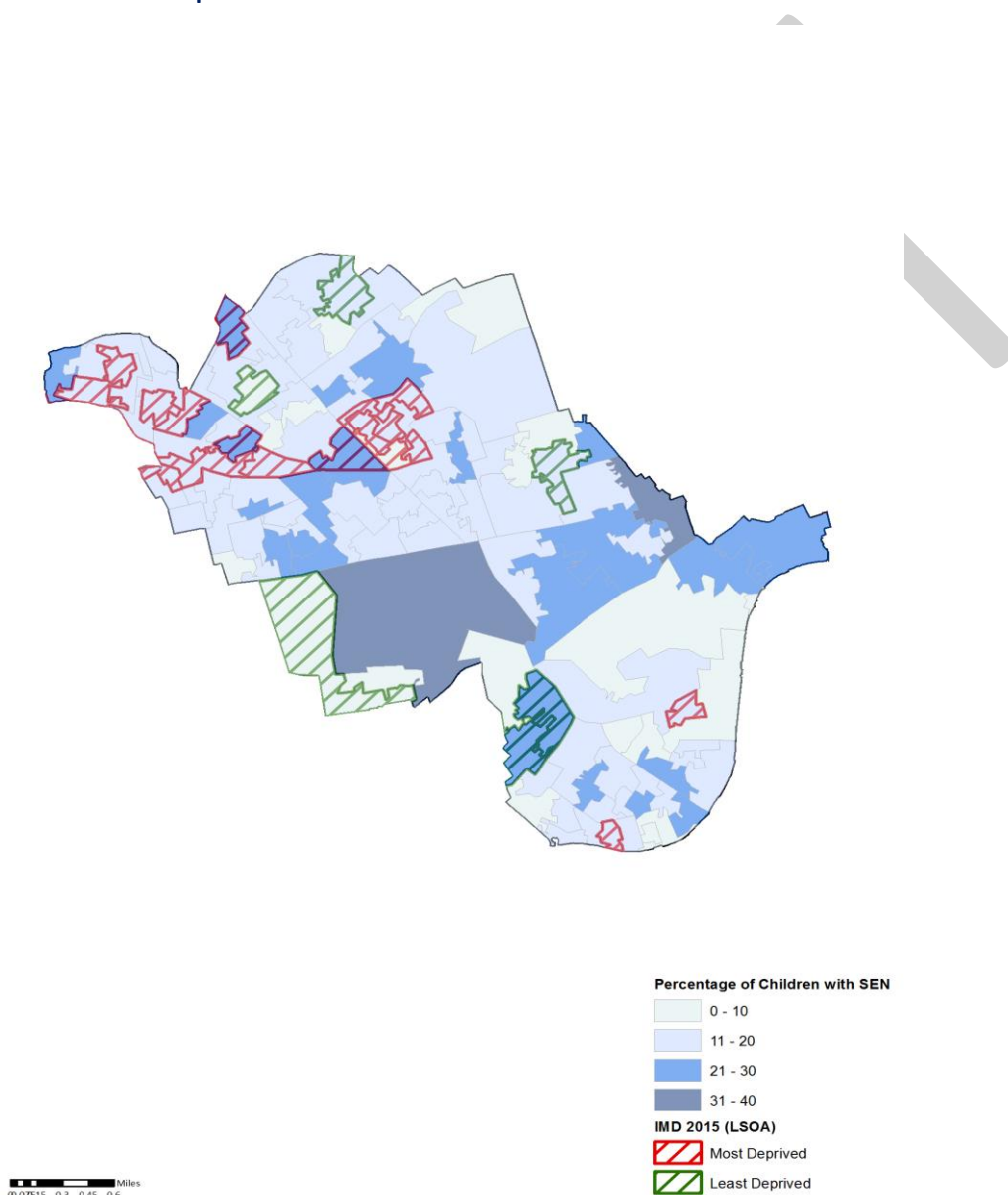
DRAFT

### 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.

- Very few children with long term health conditions live in the most deprived or least deprived areas of Westminster

**Figure 42: Children with health specific special educational needs and disabilities, cross referenced with most and least deprived areas**



Source: System one and QOF data, Central 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. 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 Children with Medical Conditions at Schools” Dfe Guidance, Sept 2014). They will not require special educational provision and therefore should not be viewed as children and young people with SEND. However, in some instances there may be an overlap between students with SEN 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 1,778 children and young people recorded as having asthma, (54% male and 46% female), 4% of the CCG 0-25 population.
- Pollution can trigger asthma symptoms and all inner London boroughs, including Westminster, have high levels of pollution

Nationally, 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 **185 children and young people** recorded as having diabetes (44% male and 56% female), 0.4% 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<sup>52</sup>.

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 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<sup>53</sup>.

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<sup>52</sup> [Diabetes UK](#)

<sup>53</sup> [Diabetes UK](#)

**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

### 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.<sup>54</sup>

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<sup>55</sup>.

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<sup>54</sup> [Epilepsy prevalence, incidence and other statistics](#), Joint Epilepsy Council of the UK and Ireland, September 2011

<sup>55</sup> Epilepsy Society: School, education and epilepsy <https://www.epilepsysociety.org.uk/school-education-and-epilepsy#.WYYZOseGOUk>

## 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.<sup>56</sup>

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 or their family.

### 14.2 What do we know nationally?

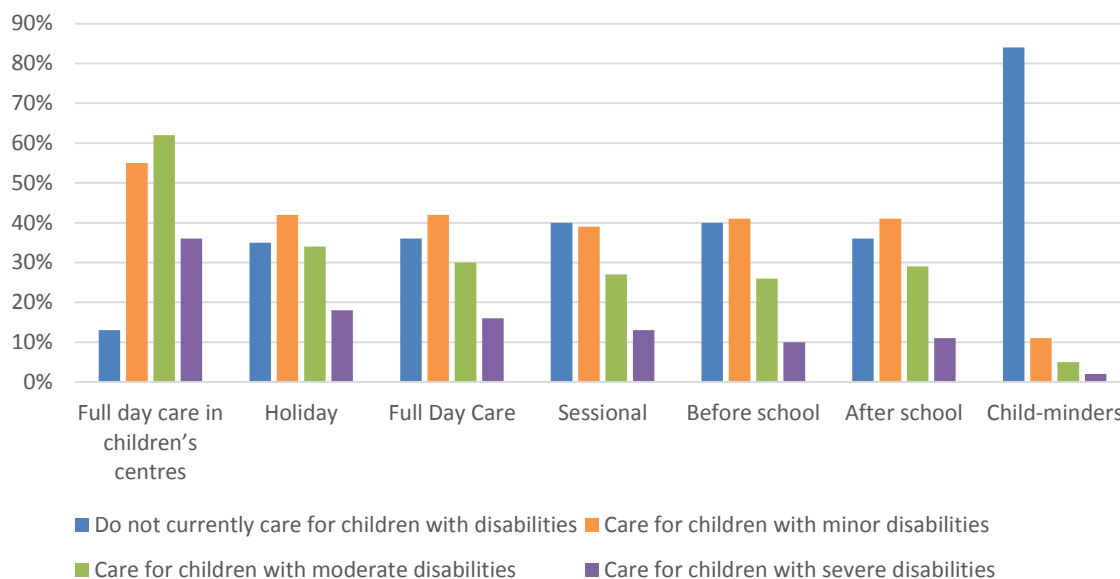
Nationally, early years' providers do not always provide for children with disabilities or cater well to children with SEN, and the rates differ across different types of providers.

- **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.

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<sup>56</sup> [National Framework for Children and Young People's Continuing Care](#), 2016, Department of Health

Figure 43: Proportion of providers caring for children with disabilities, 2013



Source: [Childcare & Early Years Providers Survey 2013](#)

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?

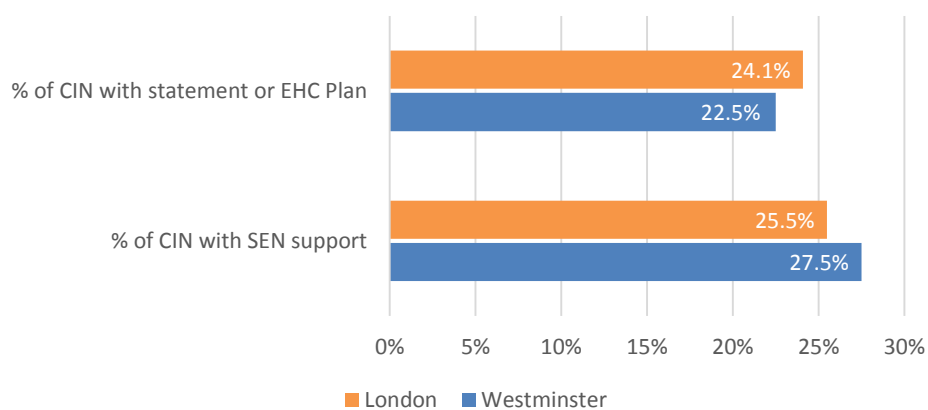
#### 14.3.1 Children in need

In Westminster, 27.5% of children in need are receiving SEN support and 22.5% of children in need have a statement of SEN or EHC plan.<sup>57</sup> 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.

<sup>57</sup> Local Government Association [Local area SEND report](#)

Figure 44: Percentage of children in need receiving SEN support, or with a statement of EHC plan 2015/16



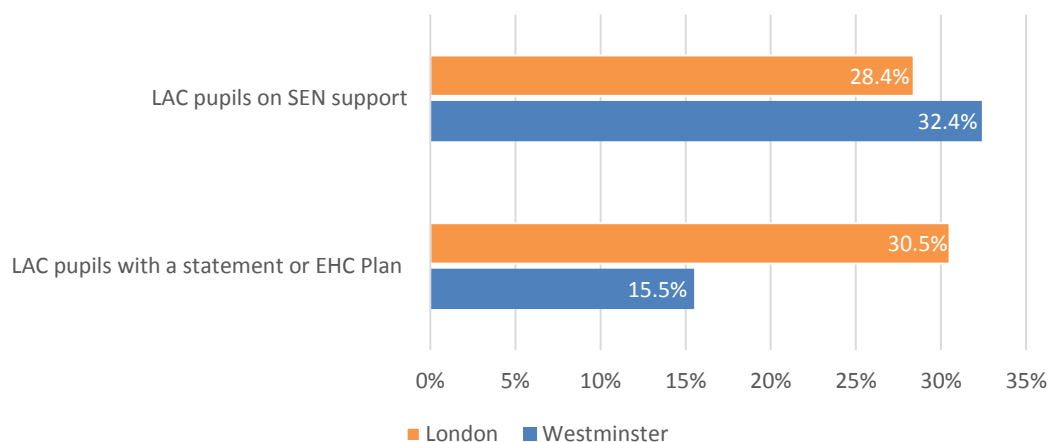
Source: Department for Education, Characteristics of Children in Need in England: Outcomes tables

### 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 Westminster, 32.4% of looked after children are on SEN support, compared to 28.4% in London. There are 15.5% of looked after children in Westminster that have a statement of SEN or EHCP, compared to 30.5% in London.



**Figure 45: Percentage of looked after children with a statement or EHC plan, or receiving SEN services (2015/16)**



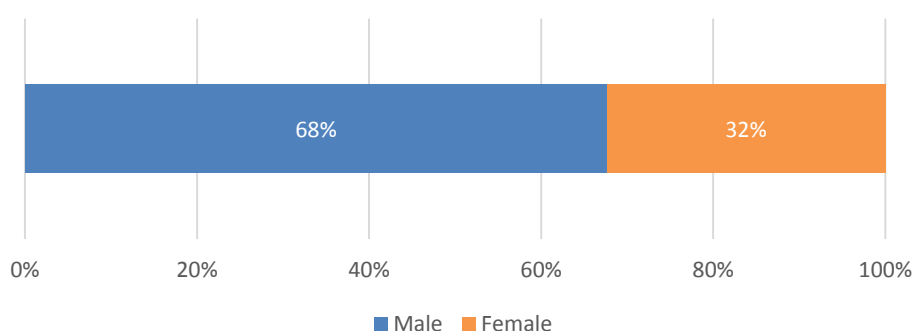
Source: Department for Education, Outcomes for Children Looked After by Local Authorities in England

### 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 189 children in need in 2015/16 and 209 in 2016/17. As of September 2017/18, the team were working with 200 children in need.
- 10.5% of children in need have a disability<sup>58</sup>
- As at 31<sup>st</sup> March 2017, there were more boys than girls receiving social care support from the Disabled Children’s Team.

**Figure 46: Proportion of males and females receiving support from Children’s Disabled Team as at 31<sup>st</sup> March 2017**

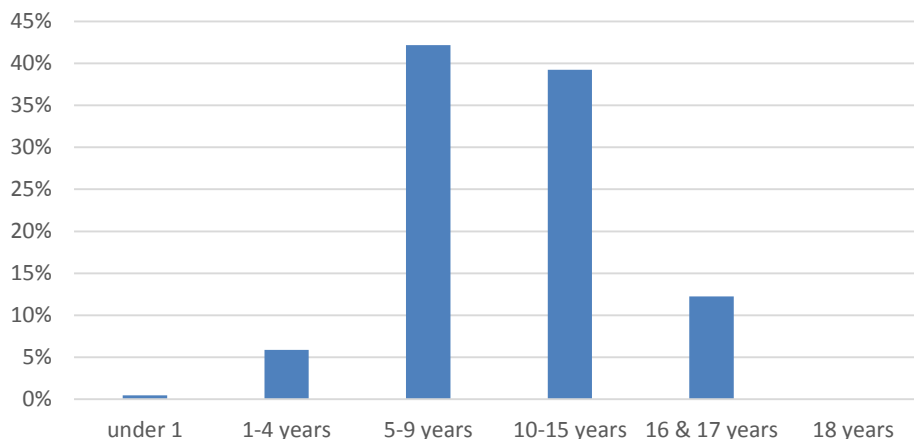


Source: Westminster’s Children’s Services Business Intelligence, November 2017

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

<sup>58</sup> Department for Education, Characteristics of Children in Need in England for year 2016/17

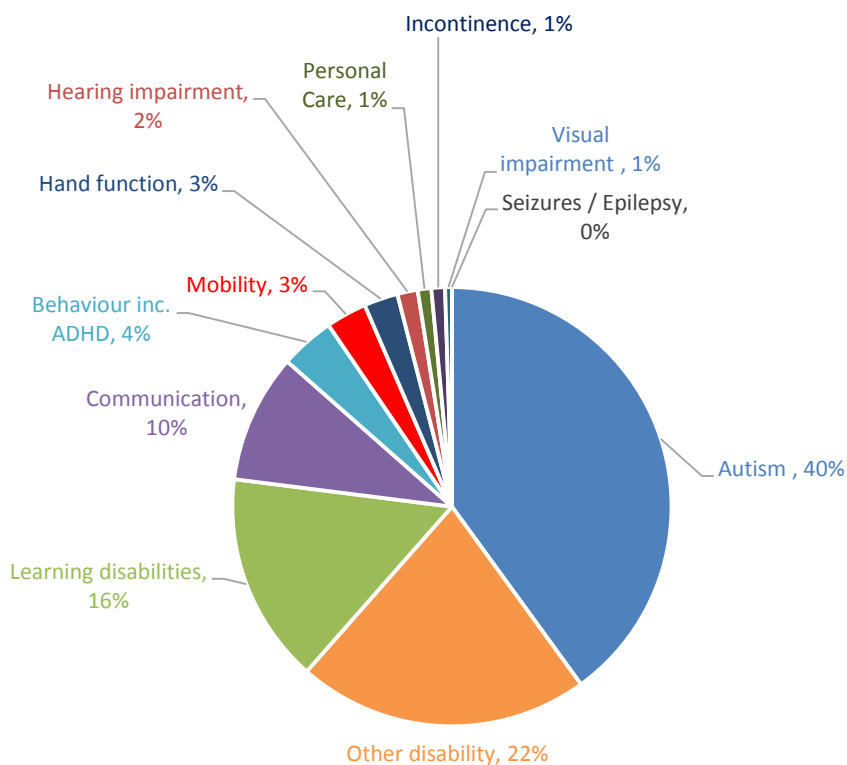
Figure 47: Proportion of children in need receiving support from the Children’s Disabled Team, by age as at 31<sup>st</sup> March 2017



Source: Westminster’s Children’s Services Business Intelligence, November 2017

- Majority of social care cases are for autism, learning disabilities and other disabilities

Figure 48: Proportion of social care cases in Westminster by type as at 31<sup>st</sup> March 2017



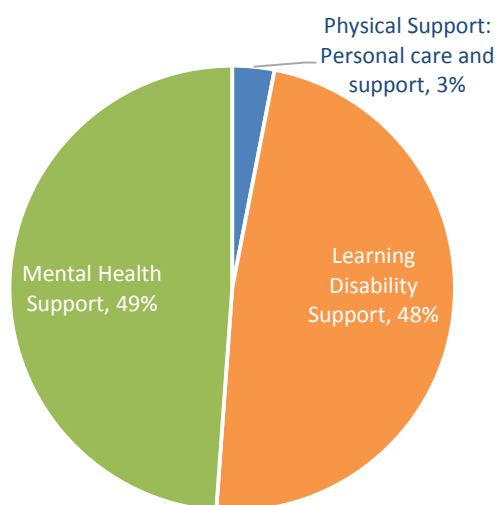
Source: Westminster’s Children’s Services Business Intelligence, November 2017

### 14.3.4 Care needs of young people aged 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 Westminster receive social care support for mental health and learning disabilities. A small percentage (3%) receive support for physical support.
- 3% of young people accessing learning disability support and 2% of young people accessing mental health support, do so in residential care

Figure 49: Percentage of social care users in Westminster aged 18-25 by primary support



Source: Short and long term return LTS001B at year end (31<sup>st</sup> March 2017) by primary support reason

INSERT case study on Community Learning Disability Service

## 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 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 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 et al)

These demands on the parent or carers time reduces their resources and energy available for other activities such as 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 (Troy 2007). Parents can feel stigmatised 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 (Gray 2002).

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?

Contact with other parents 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 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 Westminster, the following areas were identified as priority themes by the Parent Forum:

- Access to wider Local Offer – e.g. Parks
- Transition to adulthood

*“The absence of support, advice and guidance for young people and their families as they prepare for adulthood is a very real gap in the Local Offer”*

- Lack of provision in the South of the borough

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 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 Scotland 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 et al, 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

## 16 Appendices

### 16.1 Appendix 1: Engagement

#### 16.1.1 Launch event: Stakeholder Workshop, January 2017

A workshop was held on 27<sup>th</sup> 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 Westminster Parent Participation Group 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....
<p><i>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.</i></p> <p><i>Wider consultation with parents including on the Local Offer has been good but needs to be coordinated to make best use of our time.</i></p>	<ul style="list-style-type: none"> <li>• 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.</li> <li>• Review and rationalise the involvement of parents across the CFA Programme.</li> </ul>
<p><i>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.</i></p> <p><i>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 &amp; contributions, and the confidence/trust to work</i></p>	<ul style="list-style-type: none"> <li>• Work with schools to make sure:                             <ul style="list-style-type: none"> <li>○ there is up to date SEN Information Report for all schools on the local offer website</li> <li>○ they make best use of the wider SEND resources available to them locally to support children in a mainstream setting</li> <li>○ review the effectiveness of our commissioned SEN outreach</li> </ul> </li> </ul>

<p><i>The current panel processes can feel quite slow &amp; unresponsive.</i></p>	<ul style="list-style-type: none"> <li>Act on the findings of the current review of panel processes including appropriate delegated authority and improved recording.</li> </ul>
<p><i>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.</i></p>	<ul style="list-style-type: none"> <li>Follow up parent’s suggestion that individual Health Care Plans attached to the EHC Plan.</li> </ul>
<p><i>Access to Speech and Language assessment &amp; therapy where a child or young person is not eligible for an EHC Plan is harder than under pre CFA arrangements.</i></p>	<ul style="list-style-type: none"> <li>Undertake a whole system review (CCG, Local Authority and individual schools) of current commissioning and provision.</li> </ul>

## 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 Westminster’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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