

# Health & Wellbeing Board Agenda

## Monday 9 September 2019 at 6.00 pm Meeting Room 2 (2nd Floor) - Shortlands

### **MEMBERSHIP**

Vanessa Andreae - H&F Clinical Commissioning Group (Vice-Chair) Dr James Cavanagh – Chair of the Governing Body, H&F Clinical Commissioning Group Councillor Ben Coleman - Cabinet Member for Health and Adult Social Care (Chair) Councillor Adam Connell - Cabinet Member for Public Services Reform Janet Cree - H&F Clinical Commissioning Group Councillor Larry Culhane - Cabinet Member for Children and Education Steve Miley - Director of Children's Services Anita Parkin - Director of Public Health Lisa Redfern – Strategic Director of Social Care and Public Services Reform Glendine Shepherd - Head of Housing Solutions Sue Spiller - Chief Executive Officer, SOBUS Nadia Taylor - Healthwatch Representative

#### **Nominated Deputy Member**

Councillor Patricia Quigley – Assistant to the Cabinet Member for Health and Adult Social Care

Councillor Lucy Richardson, Chair, Health, Inclusion and Social Care Policy and Accountability Committee

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Members of the public are welcome to attend. A hearing loop is available and the building has disabled access.



### Shortlands

3 Shortlands, Hammersmith, London W6 8DA Closest Underground Station Hammersmith

Closest Bus Stop Latymer Court (Stop G)

Date Issued: 04 September 2019

## **Health & Wellbeing Board**

## Agenda

#### <u>ltem</u>

#### 1. MINUTES AND ACTIONS

- (a) To approve as an accurate record and the Chair to sign the minutes of the meeting of the Health & Wellbeing Board held on 25 June 2019; and
- (b) To note the outstanding actions.

#### 2. APOLOGIES FOR ABSENCE

#### 3. DECLARATIONS OF INTEREST

If a Member of the Board, or any other member present in the meeting has a disclosable pecuniary interest in a particular item, whether or not it is entered in the Authority's register of interests, or any other significant interest which they consider should be declared in the public interest, they should declare the existence and, unless it is a sensitive interest as defined in the Member Code of Conduct, the nature of the interest at the commencement of the consideration of that item or as soon as it becomes apparent.

At meetings where members of the public are allowed to be in attendance and speak, any Member with a disclosable pecuniary interest or other significant interest may also make representations, give evidence or answer questions about the matter. The Member must then withdraw immediately from the meeting before the matter is discussed and any vote taken.

Where members of the public are not allowed to be in attendance and speak, then the Member with a disclosable pecuniary interest should withdraw from the meeting whilst the matter is under consideration. Members who have declared other significant interests should also withdraw from the meeting if they consider their continued participation in the matter would not be reasonable in the circumstances and may give rise to a perception of a conflict of interest.

Members are not obliged to withdraw from the meeting where a dispensation to that effect has been obtained from the Audit, Pensions and Standards Committee.

#### <u>Pages</u>

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#### 4. BETTER CARE FUND

To Follow This report provides a progress update on the Integration and Better Care Fund Plan for 2017-19 submitted on 11 September to NHS England and the Department of Communities and Local Government. The Better Care Fund was announced in June 2013 "to drive the transformation of local services to ensure that people receive better and more integrated care and support.

#### 5. PRIMARY CARE NETWORK

This report provides an overview of Primary Care Networks and explains how they will be organised in Hammersmith and Fulham.

#### 6. DRAFT CHILDREN AND YOUNG PEOPLE WITH SPECIAL EDUCATIONAL NEEDS AND DISABILITIES (SEND) JOINT STRATEGIC NEEDS ASSESSMENT (JSNA) REPORT

This report provides oversight of the development and use of the Joint Strategic Needs Assessment (JSNA) by the Council and the H&F Clinical Commissioning Group (CCG).

#### 7. WORK PROGRAMME

The Board is requested to consider the items for its work programme and suggest any amendments or additional topics to be included in the future.

#### 8. DATE OF NEXT MEETING

The Board is asked to note the date of the next meeting of the Board which will be on Wednesday, 6 November 2019.

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## London Borough of Hammersmith & Fulham

Health & Wellbeing Board



Tuesday 25 June 2019

#### PRESENT

**Committee members:** Vanessa Andreae, H&F CCG Councillors Ben Coleman, Cabinet Member for Health and Adult Social Care (Chair) Janet Cree, H&F CCG Larry Culhane, Cabinet Member for Children and Education Anita Parkin, Director of Public Health Keith Mallinson, H&F Healthwatch Representative Steve Miley, Director of Children's Services Lisa Redfern, Strategic Director of Social Care Glendine Shepherd, Assistant Director of Housing Sue Spiller, Chief Executive Officer, SOBUS

#### **Nominated Deputies Councillors:**

Lucy Richardson Patricia Quigley

Officers in attendance: Nicola Ashton, Strategic Commissioner, ASC

**Guests:** Mark Easton, Chief Accountable Officer, North West London Collaborative of CCGs; Olivia Clymer, Chief Executive Officer, Healthwatch; and Nadia Taylor, Healthwatch.

#### 1. <u>APPOINTMENT OF VICE CHAIR</u>

Janet Cree reported that Dr Tim Spicer would be stepping down from his role as Chair of the Hammersmith and Fulham Clinical Commissioning Group governing body and that Dr James Cavanagh had been appointed as the new Chair. Keith Mallinson reported that this would be his last meeting as the Healthwatch representative for the Health and Wellbeing Board. Nadia Taylor confirmed as the new representative.

Janet Cree reported that Dr Tim Spicer would stepping down from his role as Councillor Coleman thanked Dr Spicer for both his contribution to the work of the Health and Wellbeing Board, facilitating transparent debate, and commended his commitment to the residents of Hammersmith and Fulham. Councillor Coleman also thanked Keith Mallinson for his unstinting support

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and commitment as the Healthwatch representative and looked forward to welcoming Nadia Taylor to her first meeting as a member of the Board in September.

#### RESOLVED

That Vanessa Andreae be elected vice-chair of the Board.

#### 2. <u>MINUTES AND ACTIONS</u>

Under the item on Opening Doors London, "pride and practice" was amended to "pride in practice"

As a matter arising, Anita Parkin reported that the Council was in dialogue with Opening Doors London regarding a proposal to establish two support groups for the LGBTQ+ (lesbian, gay, bisexual, transgender or queer) community in two locations. The initial views were that each group would be supported by a small team of volunteers and based on identified, local need. Development of the proposals will also align with pride in practice, and care quality standards. An update will be reported to the Board in the autumn.

#### RESOLVED

That the minutes of the previous meeting were agreed as an accurate record.

#### 3. <u>APOLOGIES FOR ABSENCE</u>

Apologies for absence were noted from Dr Tim Spicer.

#### 4. DECLARATIONS OF INTEREST

None.

#### 5. SOCIAL ISOLATION AND LONELINESS UPDATE REPORT

Anita Parkin confirmed that the report author, Fraser Serle, was leading this work, which was a top priority for the Borough. It was well recognised that there was a clear correlation between health inequalities and social isolation and loneliness (SIL). The Board had considered SIL in March 2019. Following engagement work, stakeholders had been involved in workshop discussions and an updated delivery action plan was being drafted, to be brought back to the Board later in the year.

The aim was to precipitate a change in culture within the Borough and to embed this, working with all ages, and social groups such as young people, older people and carers. This would recognise that SIL was an issue that was a community wide concern. This was not about achieving a quick fix but about building a borough identity. A bid for the national lottery was being developed to secure resources.

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Anita Parkin reported that they were also working closely with emergency services and that she had met with Helen Harper, Borough Commander. Emergency services often worked with vulnerable individuals who might experience SIL. In collaboration with established groups, the work might potentially alleviate some of the pressure on blue light services. The Council was also examining social value indicators within its own contracts, encompassing all areas of social commissioning. The Economy Department was looking at a service model which could link up communities, not just those in social housing, and explore how the Council signpost support.

Janet Cree referred to paragraph 4.4 and social prescribing within the NHS. It was explained that there had been discussions to explore how social prescribing could be linked into wider provision. More resources would be made available as part of the development of primary care networks (PCNs) to collate information in an accessible way for residents. This will be in a leaflet format and could help signpost services for SIL. Further details would be reported to the Board in due course. Sue Spiller welcomed the concept an information leaflet and suggested that it include references to what was available in the voluntary sector. In addition to highlighting their work, the leaflet could be distributed through local third sector voluntary groups and organisations and help make them more visible.

It was observed that some residents who experienced SIL did not fit into categories for example, older people. Anita clarified that this point had been identified in the original strategy (considered by the Board in March 2017) and that this was cross-cutting issue that affected a broad range of different groups. The key was to understand how to signpost residents to SIL support services, connecting them to local, community events within the Borough. Lisa Redfern confirmed that Council aimed to be an exemplar. Many staff lived outside the Borough and commuted significant distances, balancing work and life priorities. While they would not necessarily have an SIL condition, the Council wanted to raise the profile of SIL need and how to harness the support that existed. Councillor Coleman commented that this was an important strand of the Council's work which aimed to better support staff so that they felt less isolated.

Vanessa Andreae commented on an organisation called Kindred which had recently established itself in Bradmore House, Queen Caroline Street. A membership club, they hosted a range of social events which was open to members. Membership allowed use of facilities which included a library, restaurant and quite spaces for working age professionals who wanted to network. Janet Cree observed that there were similar concerns about the health and wellbeing of CCG staff and how to support them, although they were smaller in number.

#### RESOLVED

That the report be noted.

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#### 6. <u>NW LONDON COMMISSIONING REFORM PROGRAMME: PUBLIC DRAFT</u> <u>CASE FOR CHANGE</u>

Mark Easton provided an overview of the Case for Change from the North West London Collaboration of CCGs (NWL Collaborative). Commenting on the title he explained that this should be re-titled as it was not a "draft" document. As the consultation continued, further information would be incorporated as an update. The deadline of 24 July as the closing date for comments offered a mistaken impression. Comments on the Case for Change would be accepted up to 24 August, in advance of the CCG governing body meetings planned for September.

The Case for Change reflected London wide and national reform. NHS England required that CCGs indicated their views as to the proposals for CCG reform by the end of September, to feed into changes that will be implemented in April 2020. CCG governing bodies will consider whether they wish to merge by April 2020. If they agreed to merge, then GPs will need to vote to determine whether they too agreed to the proposal. NHS England will then go through an assurance process. It was explained that the NWL Collaborative was now being supported by the newly established NHS London (following a merger of regional offices).

The proposals for reform were rooted within NHS Long-Term plan (published January 2019), and referenced a significant reduction of CCGs to align with integrated care partnerships (ICPs) over the next two years. It was clear that to not accept reformation was not an option and that there was an expectation that there will be one CCG per STP (sustainability and transformation partnership, now known as integrated care systems (ICSs) area. There were five ISC areas in London and other than North West London, all of them had declared their views and agreed to accept reformation. North West London would be the last area to formally declare their position.

Mark Easton was of the view that the Case for Change would facilitate a better way of understanding how the care and health system will operate in future. Long term, the strategic aim was to promote the evolution of ICSs. At place or borough local level, this would encompass the development of links within the framework of a local PCN. Work continued to develop innovative approaches to joint commissioning and integrated provision at place based, borough level and this would form the basis of ISCs. There would be a greater emphasis on collaborative work between providers, heading towards integrated partnerships. Preceding this, there would be an intermediate stage which would encourage the development of local partnerships with the local CCGs. A scheme of delegation would be established to allow the new structure to exercise decision making powers, possibly with joint appointments and shared budgets. This was something that would need to be shaped and developed locally and would be influenced by the quality of existing, local relationships.

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Mark Easton explained the differences between what would be commissioned at North West London level and locally. Specialist services would continue to be commissioned at North West London level and community-based services, locally.

Councillor Coleman sought clarification about the timeframe for agreeing the proposals by September. He pointed out that the merger guidance produced by NHS England (Procedures for clinical commissioning groups to apply for constitution change, merger or dissolution, published April 2019) advised that the deadline was 31 October 2019 and that there was an option to implement change at the later date of April 2021. The CCGs were required by NHS England to indicate whether they wished to change by either 2020 or theoretically, elect to merge in 2021. Mark Easton responded that NHS England sought a response by April 2020, however the legal point was correct, it was technically possible for the CCGs to not respond.

Councillor Coleman enquired about what would be included in the next update. Mark Easton confirmed that the update would include more detail about the operating model that would exist at North West London and local levels, it would set out how the CCGs would undertake strong engagement, scrutiny, and describe financial structures. It would also refer to work ongoing at London level.

Keith Mallinson felt that reform proposals lacked a mechanism to facilitate democratic, local accountability. He asked about Healthwatch representation on the combined CCG and what the role of Healthwatch would be, given their statutory powers, and how this would work with regards to governance at a North West London level. Mark Easton responded that there was no blueprint to explain what the democratic framework would look like. Engagement on the Case for Change will help formulate ideas, but the final structures would need to be decided. Healthwatch representation, to illustrate, could be determined locally. Public engagement and scrutiny were also being developed and co-produced, to ensure that the patient voice was included. Vanessa Andreae referred to page 14 of the report and confirmed that in terms of governance, the ICP board will be democratic, accountable and offer a voice for all providers. The ICP board will also exercise statutory functions, which residents would not want to be involved in. Representation could include Healthwatch and councils. There would be an emphasis on shifting care to fit patients, but local infrastructures would be established as part of the transition process.

Councillor Coleman asked how a new sub-committee would align with existing structures. Mark Easton explained that the CCGs would delegate authority to the new structure under a scheme of delegation. The intention was to ensure a consistent framework for place-based provision, commissioning services based on best value care and quality of care, that was locally sourced. Exploring this further, Councillor Coleman asked what the sub-committee would do that would be different from the current delivery model, and what this could look like. In response, Mark Easton stated that the new structure would be the opposite of the current structure, with a single statutory body, operating under a scheme of delegation, commissioning local

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services. The existing decision-making process would continue but there would be more joined up working within the strategic framework of a single CCG. The new structure would also seek to put in place certain care quality standards in terms of driving up value. It was pointed out that much of this work had been on-going for some time and that this current phase was a continuation of a direction of travel that had been followed over the preceding18 months.

Councillor Coleman enquired about the financial cost of implementing and supporting the sub-committee and to what extent this had been considered. It was understood that there were plans to reduce the management cost envelope for 2021 but these costs had already been significantly reduced. Cost reductions would not be achieved through a reduction in management in what was one of the most efficient services in the world.

Highlighting concerns about the impact on residents, Councillor Richardson sought further information about the governance arrangements. It was noted that the detail of the next iteration of the document will describe government structures at a local level and set out what could be commissioned at local level. This will be a more detailed than the Case for Change. However, it was important to frame the involvement of residents within a statutory framework otherwise this would be lost. Mark Easton replied that engagement and involvement with patient groups would be embedded within the new structures, but that public engagement could not happen without the involvement of staff. It was clarified that work on the patient's citizens panel was being led by Rory Hegarty, Communications Director, H&F CCG. The number on the panel had been reduced from 4000 to 3000 and would be democratically representative, reflecting the local demographic. There had been some delay on the work, as he was currently working on a report covering issue of public engagement on the Case of Change which would shortly be considered by the CCG.

Councillor Quigley referred to a letter from Mark Easton to Councillor Coleman dated 19 June 2019 and his personal view that it was better to progress change swiftly rather than risk uncertainty for CCG staff. Councillor Quigley questioned why there was a need to move so quickly with the reform when there was an option to delay until 2021, particularly given that he stated in the same letter the need to move at a considered pace. Mark Easton confirmed that he had expressed his personal view that delaying reform could result in the loss of valuable staff. The key concern was about whether the CCGs were ready to move forward and if the reforms deliverable. If it was possible to demonstrate that change could be delivered more quickly and safely, then it should be. A decision was required by the end of September and this was a major change to determine within two months. This decision had already been taken in other parts of London but had progressed any further along in terms of development.

Referring to the letter again, Councillor Quigley pointed out that Mark Easton had stated also that he did not make decisions until he was ready to make them and queried again why the decision was being progressed so quickly. It was explained that the North West London area was the last of the five

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London areas to be taking the decision. Councillor Coleman responded that the CCG should not be influenced by the pace of decision making of the other London areas and highlighted the Council's own approach in being an outlier in not charging for home care. Mark Easton explained that the NHS was a statutory service and that it was not unreasonable to consider the evidence for change in September and then reach a decision. Councillor Coleman suggested that it should be possible to progress with greater caution, reinforcing agreement incrementally however, Mark Easton was of the view that it was reasonable to align with other parts of London, particularly if this meant retaining staff. Vanessa Andreae observed that staff had been affected by the proposed changes and uncertainty. The NHS had signalled change and it would better to navigate the reforms whilst retaining good staff. Further, Mark Easton and his team had been extremely sensitive in their dealings with the CCG and its governing body.

Olivia Clymer commented that Healthwatch would be articulating its concerns regarding the progress of the reform and highlighted that there were particular issues around assurance and quality, and what this would look like at a local level. Healthwatch welcomed details about the proposals for a new subcommittee but given that the statutory framework remained in place, the absence of a legislative driver needed to be addressed, together with the logistics. The Case for Change was not being driven by a white paper or policy document and Mark Easton offered assurance that the role of Healthwatch would not be revised and that they would be represented on the Olivia Clymer observed that the pace of change was a sub-committee. challenge, particularly in respect of the timely receipt of documents. It was clarified that while this did not prevent Healthwatch from engaging, it was a challenge to provide appropriate and timely commentary. It was noted that this was addressed, in part, with the now bi-monthly meetings of the CCG and the Chair of Healthwatch, Christine Vigers had been in dialogue with the CCG about this concern. Olivia Clymer suggested that if papers were issued earlier, this would allow more time for Healthwatch to comment.

Merrill Hammer, Hammersmith and Fulham Save Our NHS (HAFSON) observed that the proposals had been regarded as a management decision that would not impact on residents, a view that she disagreed with. The recent Joint Health Overview and Scrutiny (JHOSC, 21 June 2019) had made the point that members were being invited to comment on partially formed proposals. She continued that as a member of the public, there was little opportunity to comment on the proposals which had been drip fed or to ask questions about them, replicating the uncertainty and lack of engagement that had existed with Shaping a Healthier Future (SaHF).

Addressing this comment, Mark Easton responded that SaHF was about a service reconfiguration strategy that involved change over a ten-year period and changes to local hospitals. This was not a proposal for service change, it was about how the NHS better integrated itself with partner providers and moved away from commercial partnerships. The NHS genuinely listened to comments from Healthwatch and local government colleagues. Accepting the point about the fragmented release of information, he explained that the intention had been to put forward ideas that were emergent and could be

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shaped by the views being put forward. It was acknowledged that this approach made appear as though the CCG would come to each meeting with something new, but the aim of this was to gather information and views to shape proposals.

Lisa Redfern referred to a recent workshop held with senior staff and which Mark Easton had viewed as being 'useful'. It was stated that in her view, the workshop had not provided further clarity and little detail about the Case for change. She enquired why it was not possible to move forwards with reform without changes to the management structure. Mark Easton observed that the workshop had been an opportunity to co-design proposals with local government colleagues as to what would be appropriate at the North West London Level.

Mark Easton was asked by Councillor Coleman to highlight what the CCG was going to differently, following the workshop. He explained that the CCG valued opportunities to undertake public engagement and that the workshop had facilitated preliminary consensus, dialogue and engagement as to what could be agreed at the North West London level and locally. He reiterated that this was an opportunity to hear other views and use these to shape proposals. Decisions were currently delegated up and this will reverse the decision-making model. One of the key decision-making elements of the NWL Collaborative was that if one CCG disagreed, then alternative options would have to be considered.

Councillor Coleman sought reassurance about how patients will be consulted. There had been no information about this in the paper to indicate how this would happen, other than the Citizens Panel. Councillor Coleman compared this to a large focus group and asked about the format and decision-making structure. Mark Easton felt unable to provide full details about this as Rory Hegarty, who was leading on this work, was better placed to provide the details of how this would be established. He confirmed that Citizens Panel would represent the local demographic and allow the NWL Collaborative to test out views. The Citizens Panel would not be a decision-making body and would have no statutory powers to take decisions.

Councillor Coleman referred to NHS guidance on engagement and consultation on changes to specialist services, where there were different commissioning arrangements proposed or, for example, when a service relocated from one borough to another. It was confirmed that the NWL Collaborative would continue to commission acute and mental health services and that, by this example, there was such a service change, then this would be reviewed by a joint health overview and scrutiny committee, which could be formed by agreement between the boroughs involved.

Sue Spiller commented on level of engagement with third sector, voluntary providers by ICPs, which had been difficult. Mark Easton agreed with the view that this should be less clinically led, rather than financially driven. He continued, that if the CCGs were to decide that they were not ready to make this change, then they will not decide on the issue. It was noted that there would not be a fully developed ICP in place by April 2020 or 2021, which were

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currently being formulated. Based on good examples of new structures that had been already established in areas such as the West Country and Somerset, Mark Easton observed that the success of the changes depended on the nature of the local relationships. Those with well developed local links will move forwards fastest. Janet Cree concurred and said that it was essential to build links into the ICP, so that they could make the most of opportunities such as social prescribing.

Jim Grealy drew comparisons with the reformation of the Inner London Education Authority. He commented that he had attended three of Mark Easton's presentations discussing the changes, but greater clarity was still required. Working together was a matter of trust. Jim Grealy continued that 2.5 million people were being asked to consider a set of complex ideas. He suggested that it would be better to take the ideas and structure them in September, then advise NHS England of their intentions to plan for 2021 following full consultation. It was better, in his view, to not move quickly and work to get it right for 2021, taking along staff as it progressed. He cautioned that the alternative would be to engender further resentment with colleagues in local government and the voluntary sector who had not been adequately consulted. Mark Easton reiterated his earlier view but acknowledged that this was a fair point. He added that it might also be possible that the CCGs in September concluded that they were not ready. He agreed with the concept of taking people with them but there was also a concern that not moving quickly would mean the loss of able staff as they applied for alternative employment. The NWL Collaborative hoped to promote something that was federated and decentralised with local decision-making.

Councillor Coleman commented that he struggled to understand the proposed structure and how this was substantially different from the existing structure. If the aim was not to save costs, he asked what the point was of having a new sub-committee. This was not set out clearly in the business case which lacked detail. Mark Easton replied that the reforms should be considered in the context of what difference these would make to patients. He genuinely believed that patients suffered from multiple hand offs, and that they would benefit from integrated care and seamless transitions, for example, better information systems, using common databases, leading to seamless arrangements for patient discharge. He was committed to promoting this way of working both strategically and locally.

Lisa Redfern concurred with the idea of having integrated patient pathways but explained that there was little to prevent the formation of integrated care systems now. This was about shifting culture, which was easier to achieve in terms of small-scale structures. She queried the point regarding enhancing the provision of support for patient hand offs and it was clarified that this was about the acceleration of partnerships for ICS. There were currently eight different systems for discharging patients, with differences varying from borough to borough. Integrated working made it easier to have conversations about delayed discharges.

Councillor Coleman questioned the need for a merger of the CCGs, given that it was possible to develop a mechanism to ensure that standards were

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consistent. Mark Easton explained that different services were organised respectively at either North West London or local level and that it was about what level of organisation was appropriate at policy level. Lisa Redfern pointed out that organising a joint approach encompassing three to five local authorities and CCGs, was an effective structure which was already working towards merged services and cited the example of the Community Independence Services (CIS), which had been awarded excellent. The premise of the CCG argument was that a merger would be of benefit, but in her view, what would be the purpose of having a large CCG, when there was already ongoing work to improve integration or collaboration.

Councillor Culhane enquired about working with stakeholders. Following the earlier education themed analogy, he cited the example of academies and local government advisory boards and reorganisations which had resulted in the loss of well-regarded head teachers. Councillor Culhane cautioned against an approach that might have a similar impact and asked what would be in the next update and if this would set out the detail of how the NWL Collaborative would work with the ICP. Mark Easton responded that what they were doing was in the opposite direction of educational reform, rejecting the market and making stronger, strategic plans with the intention to redirect spending back into the NHS. The next document would set out the role of the sub-committee, the interface with the CCGs and the structure of local delegation.

The next publication was expected in July and the decision as to whether these would be held in public was not ruled out by Mark Easton although it was noted that this not a matter for him to determine. Meetings would continue to rotate between different London boroughs which will help foster engagement with local authorities. Each would be supported by a local team and led by a lead clinician. How firm this plan was would be determined in the next publication.

Councillor Coleman summarised the discussion by describing the possible challenges of taking a decision in September and the concerns about moving at pace with insufficient detail and whether this had given any encouragement to pause the process. Mark Easton referred to his letter of 19 June and paragraph that had earlier been read out by Councillor Quigley. A further query from Councillor Coleman established that the CCG had received legal guidance from colleagues who had consulted lawyers and that the legal framework had been discussed. While Mark Easton acknowledged Councillor Coleman's point about this being, in part, the opposite of localism, mergers had already taken place across the country. It was confirmed, however, that legal advice had not directly been sought and that the NWL Collaborative was not aware if other CCGs had sought legal advice.

Councillor Quigley reiterated her concerns about the impact of the reform on residents in the Borough, regardless of whether the changes were implemented in 2020 or 2021, this would have a significant impact on residents. She asked if residents will have to travel to access services in future. Mark Easton confirmed that there was nothing within the proposals that indicated that residents would have to travel to access services.

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Councillor Coleman asked if this could be guaranteed and Mark Easton confirmed that yes, this was guaranteed.

Councillor Coleman referred to an earlier comment from Mark Easton regarding the fact that initially, budgets might be separate but may later be merged. Mark Easton confirmed his opinion that the process that they were engaged in was work in progress and that it would test out agreement on services. In his opinion, it was unrealistic to move services unnecessarily. In terms of what could be guaranteed, Mark Easton explained that the reaction to the changes will form the basis of the Case for Change, but it was notable that there had existed a history of CCGs lending funds to support other CCGs.

It was understood that a provisional timeline had been mapped out and that Mark Easton would be on annual leave from 13 August, returning on 10 September, the day after the next meeting of the Board. Councillor Coleman asked if there was time to have a second round of discussions. The Board was keen to work with health colleagues, but it was important that this intent was reciprocated. Councillor Coleman commented that the compressed timeframe, which did not involve patients, was not helpful in terms of progress. He acknowledged that it was helpful that the NWL Collaborative was willing to countenance other ideas, there was not sufficient time to have proper engagement. Councillor Coleman was not convinced that there was sufficient detail to support the concept of a merger, although it was helpful to have ideas to shape the process.

Councillor Coleman asked how confident Mark Easton was that the concerns raised during the discussion might delay the process. Mark Easton repeated his earlier comment that a decision would have to be reached in September as to whether the merger might take place, and, whether this would occur in 2020 or 2021. It was pointed out that there was nothing to force compliance, however, Mark Easton repeated that there was an expectation from NHS England that the NWL Collaborative will advise them of their decision in September.

In terms of the NHS policy guidance on the merger, Councillor Coleman pointed out that if the CCGs decided to not merge, any application received after 31 October will revert to a single organisation and would therefore have longer to develop plans to merge. It was also pointed out this was another reason to allow more time. In addition, there was also no specific directive to have a CCG that was co-terminus with an ICS, so North West London could have two ISCs and two CCGs, in theory. It was conceivable that there could be several different borough-based configurations of CCGs, but the paper made no reference to the potential number of CCGs that might be possible. Mark Easton accepted this point but typically, there would be one CCG per area and a strong case would need to be made in order for an atypical configuration to be agreed. He outlined two possible scenarios:

1. Some boroughs may conclude that there was a strong argument for having a bi-borough arrangement; or

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2. In terms of CCG merger configurations, it was possible that, example, there could be a 6/2 split of CCGs, and that two CCGs could later decide to join the other six.

The above scenarios where possible outcomes in theory, but Mark Easton felt that this would unpick all the work that had taken place around the NWL Collaborative and there could be little appetite for this. Comments on the merger could be submitted up to 24 August.

Councillor Coleman thanked Mark Easton for his attendance but remained unconvinced by the Case for Change. Councillor Coleman also highlighted the fact that the timeframe might not be sufficient given that papers would need to be circulated a week in advance to the CCGs. It was accepted that substantive comments would have to be provided well in advance.

#### RESOLVED

That the report be noted.

#### 7. WORK PROGRAMME

Noted.

#### 8. ANY OTHER BUSINESS

#### a) <u>PCN Update</u>

Janet Cree provided an update on PCNs. The Primary Care Committee had recommended the configuration of of a PCN in H&F and a more substantial briefing will be provided at the next meeting of the Board. There would be five PCN covering the north, central (in two parts) and southern areas of the Borough, together with Babylon and GP at Hand, in local partnership. Each network will have a clinical director (all of whom will be GPs, and who will need to be clinicians working within the locality.

Merrill Hammer commented that in principal, HAFSON supported the establishment of PCNs. However, these would be new structures and it would be some time before they were fully implemented. This was in her view, another reason to delay the merger. Vanessa Andreae responded that networking was not a new concept and they had been established in H&F for some time.

#### b) GP at Hand

Jim Grealy asked about GP at Hand and Dr Jefferies practice, and whether this would continue to be funded from within the Borough. Janet Cree responded that funding was transparent and that the same financial arrangement was in place as for any other GP practice. The PCN finance structure was set out in the DES (direct enhanced service) but there would be an opportunity to have a more structured approach to ensure a more sustainable system. It was confirmed that there would be no restriction on

Minutes are subject to confirmation at the next meeting as a correct record of the proceedings and any amendments arising will be recorded in the minutes of that subsequent meeting.

having national, out of area patients, and this had been factored in contractually. The intention had been to recognise the fact that patients might need to travel to their local surgery for treatment or a face to face consultation. Councillor Coleman offered to forward his letter to the Secretary of State for Health to the CCG about GP at Hand and the Boroughs concerns.

#### c) Local Physiotherapy Services

Following the recent consultation on the reconfiguration of local physiotherapy services for residents, Councillor Coleman affirmed the importance of ensuring that residents were able to access physiotherapy services quickly, when needed. It was agreed to bring this back to the Board for further discussion.

#### 9. DATE OF NEXT MEETING

The date of the next meeting was noted as Monday, 9 September 2019.

Meeting started: 6pm Meeting ended: 8.55pm

Chair

Contact officer: Bathsheba Mall Committee Co-ordinator Governance and Scrutiny 2: 020 8753 5758 E-mail: bathsheba.mall@lbhf.gov.uk

Minutes are subject to confirmation at the next meeting as a correct record of the proceedings and any amendments arising will be recorded in the minutes of that subsequent meeting.

London Borough of Hammers Fulham HEALTH AND WELLBEING B 9 September 2019		hammersmith & fulham	
Report title: Primary Care Networks			
Open Report			
Classification: For Discussion Key Decision: No			
Accountable Director: Janet Cree			
<b>Update Author:</b> Matt Mead, Integrated Care Lead	Contact Det	ails: <u>m.mead@nhs.net</u>	

### 1. EXECUTIVE SUMMARY

Primary Care Networks (PCNs) are groups of general practices providing population based health care to geographical groupings of between 30,000 and 50,000 people. PCNs are part of the wider changes to the GP contract, accompanied by additional investment to enable greater provision of proactive, personalised, coordinated and more integrated health and social care.

Following the release of the Network Contract Direct Enhanced Service (DES) in March 2019 practices in Hammersmith and Fulham have organised themselves into five PCNs based on existing relationships and organised around the physical geographical locations of the practices. The Network Contract DES, which practices have signed up to in addition to their core GP contracts, applied requirements for the PCN to collectively deliver from 1<sup>st</sup> July 2019 with additional elements being added over the lifetime of the contract which is expected to be in place until at least 31st March 2024.

Initially under the Network Contract DES the PCN is provided with funding to appoint a Clinical Director, core PCN funding to support the development of the network and for the delivery of extended hours access across the whole population alongside reimbursement for additional roles.

From April 2020 PCNs will also be required to deliver the first five of seven national service specifications designed to improve health, improve quality of care and help to make the NHS more sustainable. In April 2020 this will include obligations to provide structured medications reviews and optimisation; enhanced health in care homes; anticipatory care for high needs patients; personalised care; and to support early cancer diagnosis.

Under the Network Contract DES new funding is available to PCNs to support the diversification of the primary care workforce through the recruitment of clinical pharmacists, social prescribing link workers, physician associates, first contact physiotherapists and community paramedics. The introduction of these roles will be phased across the first three years of the Network Contract DES to allow the roles to become an integral part of the core general practice staffing.

In Hammersmith and Fulham several Clinical Pharmacists are already in post and working in practices under existing national schemes who would be eligible to transfer to the PCN roles. Work is also progressing to recruit Social Prescribing Link Workers with three PCNs progressing this through the GP Federation.

PCNs also require the member practices to reflect their existing obligations for patient engagement at a population level. The CCG has taken an active role in supporting this by providing training for existing and potential Patient Participation Group (PPG) members and facilitating network level PPG discussions.

In support of the ambitious aspirations for the PCNs work is underway across NWL to support the PCN development including the creation of a development plan accompanied by access to a menu of support in identified areas. The CCG is further supporting this work through collective and individual meetings with the Clinical Directors and by aligning teams to provide an identified lead for each PCN.

PCNs are also recognised as an important building block in integrated care with the expectation that the Clinical Directors play a role in shaping and supporting their Integrated Care System. Locally this has been responded too through the refocusing of Integrated Care Partnership work at the PCN level and inclusion of the Clinical Directors at Board and workstream meetings. The GP Federation has also revised the composition of it's Board to the five Clinical Directors to ensure that it represents primary care across the borough.

#### 2. INTRODUCTION

Primary Care Networks (PCNs) are at their simplest level, groupings of local general practices and are intended to build upon the core of current primary care services and enable greater provision of proactive, personalised, coordinated and more integrated health and social care. Typically PCNs are expected to cover a population of between 30,000 and 50,000 people so that they are small enough to provide the personal care valued by patients and GPs, whilst being large enough to provide economies of scale through better collaboration between practices as well as with the wider health and social care system. Although these are the anticipated population sizes the upper limit is not a strict requirement providing that the PCN is able to organise itself operationally into smaller neighbourhood teams.

PCNs are part of the wider changes to the GP contract which provide access to extra investment in order to help address the challenges facing general practice and deliver new services. In order to do this the PCNs will enter into network contracts in addition to the core GP contracts of their member practices.

Practices in Hammersmith and Fulham have organised themselves into five PCNs, building on established relationships and organised around the physical geographical locations of the practices. The location of practices and population for each of the PCNs is shown below in Figure 1.

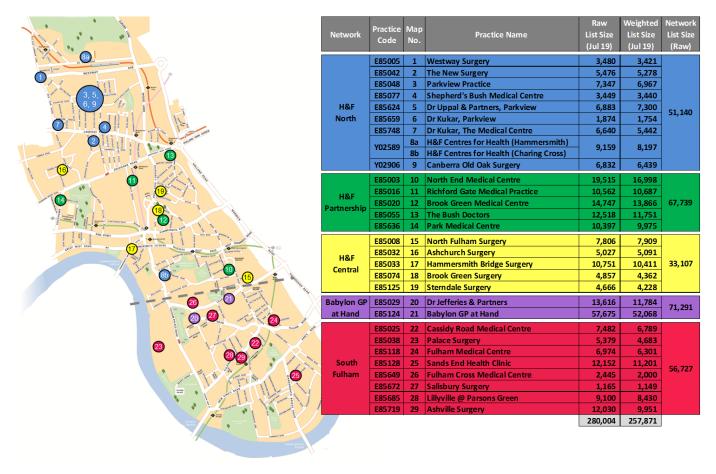


Figure 1: Hammersmith and Fulham Primary Care Networks

#### 3. NETWORK CONTRACT DIRECT ENHANCED SERVICE

In order to register as a PCN a new Network Contract Direct Enhanced Service (DES) was published in March 2019. The CCG was required to offer the practices the opportunity to register a PCN from April 2019 to enable the PCNs to sign up to deliver the contract in advance of the application of the requirements on practices from 1<sup>st</sup> July 2019. The Network DES in intended to evolve over time with additional elements being added over the lifetime of the contract which is expected to be in place until at least 31<sup>st</sup> March 2024.

The focus of the Network Contract DES in 2019/20 is to support the establishment and development of the PCNs in preparation for their role as a key delivery vehicle for the ambitions articulated with the NHS Long Term Plan.

Alongside working on organisational development the PCNs are currently delivering extended hours access across their PCN, ensuring full population coverage, and recruiting to clinical pharmacist and social prescribing link worker roles.

The Network Contract DES is supported by financial entitlements which the PCN receive into a nominated payee account on behalf of the network.

Payments to the PCN reflect funding for:

Clinical Director

Funding: 0.25WTE per 50,000 registered population or £0.514 per registered patient The PCN are required to appoint a named accountable Clinical Director to provide leadership for the PCNs strategic plans and to work with members to improve the quality and effectiveness of the network services.

- Core PCN Funding Funding: £1.50 per registered patient This funding is for use by the PCN as required to deliver the ambitions of the Network Contract DES.
- Workforce

Percentage Reimbursement based on actual salaries up to maximum amounts Under the Network Contract DES PCNs will be reimbursed to support the recruitment to new roles. Initially this is for Social Prescribing Link Workers and Clinical Pharmacists with other roles to be introduced from 2020/21.

Extended Hours Access Appointments
Funding: £1.45 per registered patient
PCNs are required to provide additional clinical sessions outside of core contracted
hours to all registered patients within the PCN.

In addition to the funding provided to the PCN, funding is also available for practices to support their participation and active membership of their PCN equivalent to £1.761 per registered patient.

#### 4. FUTURE REQUIREMENTS

Following the initial period of development the PCNs will be required to deliver seven national service specifications with five starting in April 2020 and the remaining two starting in April 2021.

The seven specifications are focused on areas where PCNs can have a significant impact on improving health and saving lives; improving quality of care for people with multiple morbidities; or helping to make the NHS more sustainable. Each of the specifications will include national processes, metrics and expected quantified benefits for patients.

Table 1: Network Contract DES Service Specifications

	2020/21	2021/22
Structured Medications Review & Optimisation		
Enhanced Health in Care Homes		
Anticipatory Care		
Personalised Care		
Supporting Early Cancer Diagnosis		
CVD Prevention & Diagnosis		
Tackling Neighbourhood Inequalities		

The specifications are to be developed with the General Practitioners Committee England as part of the annual contract negotiations and have yet to be released. In preparation the CCG is working with PCNs to ensure their readiness to deliver the specifications including support through the Integrated Care Partnership (ICP) to develop multi-disciplinary teams. The CCG is anticipating providing additional support to the PCNs to prepare for delivery when the specifications are released.

#### 5. WORKFORCE

The additional requirements for general practice under the Network DES are accompanied by new funding to support the diversification and recruitment to new roles to work across the PCN. Initially this is for clinical pharmacists and social prescribing link workers in 2019/20, expanding to include physician associates and first contact physiotherapists in 2020/21 and community paramedics in 2021/22.

These roles have been identified based on the demand for these roles within general practice and their ability to reduce the burden of the GP workload and improve practice efficiency. It is expected that over the course of the Network Contract DES that these roles will become an integral part of the core general practice.

The reimbursement available to PCNs will fund 70 per cent of these roles, with the exception of social prescribing link workers which are 100 per cent funded through the DES, up to maximum values. For 2019/20 this is the relevant percentage reimbursement of one Whole Time Equivalent (WTE) Clinical Pharmacist and one WTE social prescribing link worker per PCN. In most cases the reimbursement is required to fund new rather than existing roles with Clinical Pharmacists funded through alternative reimbursement schemes the only exception.

	Funding	2019/20	2020/21	2021/22
Clinical Pharmacists	70%			
Social Prescribing Link Workers	100%			
Physicians Associates	70%			
First Contact Physiotherapists	70%			
Community Paramedics	70%			

Table 2: Network Contract DES Additional Roles Reimbursement

From 2020/21 the network will be given greater flexibility to decide how many of each of the additional staff to recruit under the Network Contract DES with each network being allocated a single combined maximum reimbursement sum covering all five staff roles.

In Hammersmith and Fulham there already a number of clinical pharmacists in post working in a number of practices under existing national schemes who would be eligible to transfer to receive the Network Contract DES reimbursement. The CCG is working with practices and PCNs to discuss the potential transfer and to support them in developing new ways of working for the Clinical Pharmacists to deliver services across the PCN not for a single practice.

Work to recruit Social Prescribing Link Workers is also progressing locally with the recruitment for three PCNs being organised through the GP Federation and the remaining PCNs advertising independently. Opportunities to enhance and supplement these roles with additional funding are also being discussed as part of an ICP workstream to develop a Compassionate Communities model.

#### 6. PCN PATIENT INVOLVEMENT

The PCNs are expected to reflect the existing patient engagement requirements of their member practices through their primary medical services contracts. In practice this means that the PCNs are required to engage, liaise and communicate with their collective registered population, including 'seldom heard' groups, in the most appropriate way to inform and involve them in developing new services or changes related to service delivery.

The CCG has been very active in supporting practices and PCNs with these requirements particularly in relation to the development of well supported Patient Participation Groups (PPGs). This has led the CCG to develop a coaching style PPG Leadership course, based on the London Leadership Academy model, to help residents develop the collaborative working skills required to be an effective PPG member. In developing this training the CCG has worked closely with some particularly active PPG Chairs which has supported them in developing networks with other PPGs in line with the PCNs.

Accessible communications about PCNs are also being coproduced with patient and voluntary sector representatives to ensure a wider understanding of the broader context of practice engagement.

#### 7. NWL SUPPORT

Alongside the additional funding within the Network Contract DES, across NWL there is a clear programme of work to support the PCNs and help deliver the ambitious aspirations for PCNs as part of the wider system.

In order to support this the PCNs are being asked to undertake a maturity matrix assessment to establish development needs and have a clear idea of where they are aiming to get to through the implementation of a development plan. Having identified the goals and

development support for the PCN the networks will then have access to a menu of support based on a series of domains:

- PCN Set-up
- Organisational Development & Change Management
- Leadership development
- Collaborative working (MDTs)
- Population Health Management
- Asset based community development and social prescribing
- Clinical Director development

Support will be allocated on the basis of agreed principles that ensure that the success and progress against the PCN development plans are measureable, is targeted at achieving strong team-working with partners and enables the PCN to understand their population to reduce unwarranted variation.

Table 3: Timetable for PCN Development Support

Milestone:	Completion:
PCN & Community Partners undertake PCN assessment	August / September 2019
PCN Development Plan reviewed at Integrated Care Partnership	September 2019
PCN Development Plans submitted to Health and Care Partnership	October 2019
Development Support Mobilised	Late October 2019
Progress against PCN Development Plans reviewed and areas for additional support identified including sharing learning and best practice.	October 2019 – March 2020

As part of the support offer PCNs are also being asked to consider how their development could contribute to the Health and Care Partnership priorities particularly in achieving the improvement in clinical outcomes for:

- Urgent Care
- Outpatient Care
- Supporting people with frailty
- Diabetes
- Last Phase of Life and Enhanced Health in Care Homes
- Cardiovascular disease and respiratory disease
- Personalisation
- Mental Health
- Cancer
- Children's Health
- Musculoskeletal Health

In addition to the NWL level support we are also supporting the PCNs locally having met with the Clinical Directors to establish ways of working to ensure a collaborative relationship

between the CCG and PCNs. To further this collaborative approach we have also organised our Primary Care and Commissioning and Delivery Teams to align to the five PCNs with an identified lead from each team for each PCN.

#### 8. PCNs AND INTEGRATED CARE

PCNs are recognised within the NHS Long Term Plan as an essential building block of every Integrated Care System with the expectation that the Clinical Directors play a critical role in shaping and supporting their Integrated Care System.

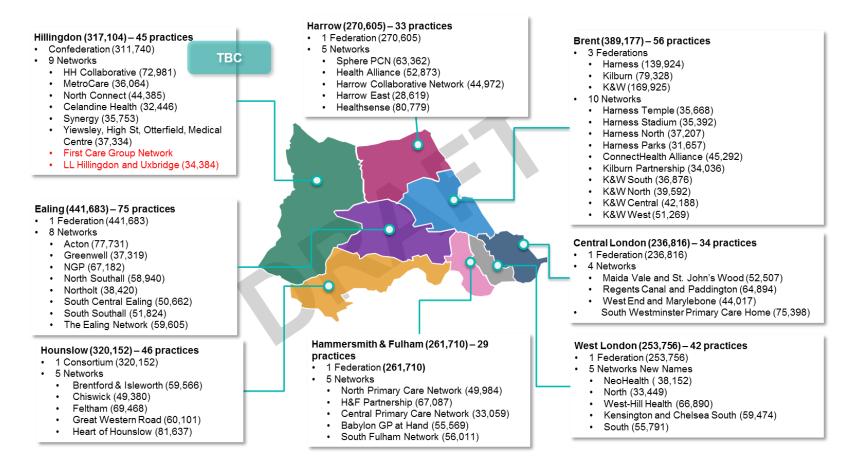
The importance of alignment of the work of the H&F Integrated Care Partnership (ICP) with the development and plans of the PCNs has been recognised with the clinical directors of each PCN invited to attend at both Board and workstream level ICP meetings. In further support of this the H&F GP Federation has revised it's constitution with the five PCN Clinical Directors now forming the Federation Board.

Progress has also been made to refocus partnership working activity at a network level, allowing the PCNs to focus of delivering care to reflect local need, and established workstreams to address priority areas. These priorities are based on steps towards a place based model of care, bringing together staff from across health and social care with the voluntary sector and the community.

- Social Prescribing utilising the opportunity provided by the social prescribing link workers funded through the Network Contract DES, and potential additional investment from Macmillan to further increase the link worker workforce, this workstream is intended to support the development of a borough level architecture to effectively utilise community assets and support community activation and development.
- Integrated Community Teams this workstream will look to accelerate the integrated working at PCN level through the creation of place based teams encompassing staff across health, social and voluntary sector organisations. Initially building the links between community health services the workstream will look to deliver improved outcomes for the patients alongside improving staff experience and improving the system efficiency.
- Integration of acute services with Primary Care Networks building on the foundation of the other workstreams, this will look to fast-track the integration by bringing in acute services in order to draw resources out of hospital and avoid unnecessary acute activity.

The formation of the Primary Care Networks provides an exciting opportunity to support GP at scale working and deliver a standardised offer of primary care to the residents of Hammersmith and Fulham with practices working together, and with partners, to harness their respective strengths.

## Where we are now – Primary Care Networks



# Agenda Item 6

London Borough of Hammersmith & Fulham HEALTH AND WELLBEING BOARD 9 September 2019		hammersmith & fulham
Draft Children and Young People with Special Educational Needs and Disabilities (SEND) Joint Strategic Needs Assessment (JSNA) Report		
Open Report		
<b>Classification:</b> For Discussion <b>Key Decision:</b> No		
<b>Accountable Director:</b> Steve Miley, Director of Children's Services and Anita Parkin, Director of Public Health	Contact Det Mandy.Lawso Nicola.Ashton	n@lbhf.gov.uk /

## 1 Summary

- 1.1 In accordance with the statutory duties and powers given to the Health and Wellbeing Board by the Health and Social Care Act 2012, the Board's terms of reference in Hammersmith & Fulham's constitution include overseeing the development and use of the Joint Strategic Needs Assessment (JSNA) by the Council and the H&F Clinical Commissioning Group (CCG).
- 1.2 The Board is asked to review, comment on and endorse the draft SEND JSNA which can be found in Appendix 1.
- 1.3 This needs assessment supports the development of a Joint Local Authority and CCG commissioning strategy for children and young people with complex needs. It describes the trends and characteristics of SEND in H&F compared to the national picture; the current service provision and identifies gaps in services and areas of unmet need.
- 1.4 This needs assessment was drafted in 2017. It has informed the development of the Sovereign arrangements for SEND in H&F which are governed by the Joint SEND

Inclusion Board overseeing the development of the SEND Inclusion Strategy and Joint Commissioning programme to address the findings of the JSNA.



# Children and Young People with Special Educational Needs and Disabilities

Joint Strategic Needs Assessment (JSNA) Report

London Borough of Hammersmith & Fulham Hammersmith and Fulham Clinical Commissioning Group

www.jsna.info

#### This report

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

It specifically aims to describe:

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

Data was collected from several 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, and 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.

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#### **1** Executive summary

#### 1.1 This document

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.

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

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

#### 1.2 Main findings

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

- 3,257 pupils in Hammersmith & Fulham schools have a special educational need (16% of school population)
- 5,060 children and young people in the Hammersmith & Fulham CCG boundary (9% of 0-25 CCG population) are known to their GP to have a SEND need (a higher figure than above due to including young people up to the age of 25)
- There are 3,900 children aged 3 and 4 that are benefitting from funded early education in Hammersmith & Fulham. Of these, 0.7% have an EHC plan and 8.1% are receiving SEN support
- There are significantly 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 Hammersmith & Fulham (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 Hammersmith & Fulham (29% of state-funded secondary school pupils with SEN)
- Hammersmith & Fulham has slightly higher participation in education or training amongst 16-17 year olds with SEND (97%) than the London or national average
- Only 62% of Education, Health and Care Plan assessments in Hammersmith & Fulham were conducted within the statutory time of 20 weeks (in 2017), however this has improved from 33% in 2016 (which compared to 48% across London in 2016)
- 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 for over 4.5 year olds in 2017/18

#### 1.3 Key messages

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

Theme	Gaps, challenges and opportunities
Early identification, diagnosis and post diagnosis support	<ul> <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.</li> <li>There needs to be a reduction in waiting times for ASD assessments, clear and accessible information on the ASD diagnostic pathway, 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> </ul>

<sup>&</sup>lt;sup>1</sup> National Institute for Health and Care Excellence: Autism spectrum disorder in under 19s: recognition, referral and diagnosis

	<ul> <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>
Information and signposting	<ul> <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.</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</li> </ul>
Service provision	<ul> <li>signpost families to the support available</li> <li>Population turnover, or 'churn', in and out of the borough necessitates</li> </ul>
provision	effective planning for a seamless transfer of children and young people with SEND into their new host borough. In 2016, 15% of the population of Hammersmith and Fulham left the borough (including 1029 aged 0-24) and 14% of the population moved in (including 1,228 aged 0-24)
	• Schools and colleges need to improve the quality, accessibility, and transparency of what the 'offer' is in each educational setting. This could be addressed through an audit on SEN Information Reports; identification of best practice; and co-production of parent friendly guide to what they can expect for a child or young person on SEN Support or with EHC Plan
	• Forecasts show an increasing number of children with SEND, and specifically ASD, LD, SEMH and SLCN. It is important that future planning; capital funding and workforce development activities capacity build existing services to accommodate the projected growth in the cohort(s)
Transition	• Among some parents of children and young people with SEND there is uncertainty and a lack of confidence over the transition process to adulthood. Further joint working between Children's Services, Adult Social Care, health providers and commissioners, 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/LBH&F PFA governance
	• Pathways post 16 are not focused sufficiently well on preparing those on SEN Support and those with EHC Plans for adult life. Further work, led by the PFA stakeholders, could develop pathways for specific cohorts of young people (post 16) with SEND:
	High Functioning Autism

	<ul> <li>Complex needs and requiring medical interventions</li> <li>SLCN</li> <li>PMLD</li> </ul>
Wider impact of SEND	<ul> <li>Children and young people with a special educational need and/or disabilities 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, and more</li> </ul>
	likely to have contact with the youth justice system. A Local Authority lec speech and language Task & Finish Group has been created which aims to establish a SaLT pathway, it is recommended the group address these challenges.
Further research	• There is a higher percentage of children in H&F with specific learning difficulties in comparison to the national average. More detailed research and analysis on the needs of this group is required to inform service design and delivery.
	<ul> <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> </ul>
	• A comprehensive and combined SEND database, across education, health and care, similar to Warwickshire's database, would help plan for the future

#### 2 Introduction

#### 2.1 Summary of legislation and guidance

The <u>Special Educational Needs and Disability (SEND) Code of Practice</u> (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 Hammersmith and Fulham, going to school in Hammersmith & Fulham and those registered with a GP at Hammersmith and Fulham CCG. 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.

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

The Act has replaced the Statement of Educational Needs with the Education, Health and Care Plan (ECHP). Since 1<sup>st</sup> September 2014, all new statutory assessments have been made under the new system. Children with existing statements have been transferred to EHCPs over the course of a three-year transition (Health & Wellbeing Boards SEND 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 <u>S.22</u>)

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 <u>S.23</u>)

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 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 <u>Care Act 2014</u> 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 <u>S.58</u>). NICE offers guidance on <u>Transition from children's to adults' services for young people using health or social care services</u> (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.

# 2.2 Local strategies

The Joint Health and Wellbeing Strategy (2016-21) has 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.

# **3** Overview of SEND population

#### 3.1 Summary

For information on the general population context please visit isna.info

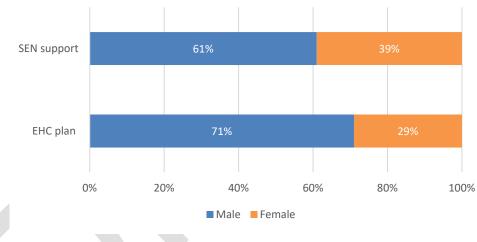
<sup>&</sup>lt;sup>2</sup> Council for disabled children

- > There are 55,015 children and young people aged 0-25 in Hammersmith and Fulham<sup>3</sup>
- There are 5,060 children and young people known to their GP within the Hammersmith & Fulham CCG boundary with SEND needs including: autism, learning disabilities, physical disabilities, sensory impairments and mental health (November 2017)<sup>4</sup>
- There are 340 2, 3 & 4-year olds with special educational needs (8% of total children benefitting from funded early education)
- > There are 3,257 pupils with special educational needs, approx. 16% of the school population
- There are 776 children and young people for whom the local authority maintains a statement of SEN, or EHC Plan, 0.5% of children and young people with statements or EHC plans who live in Hammersmith & Fulham are educated elsewhere

#### 3.2 Gender

There are significantly more boys than girls with EHC plans and SEN support amongst the school population, this is the case across London and the UK





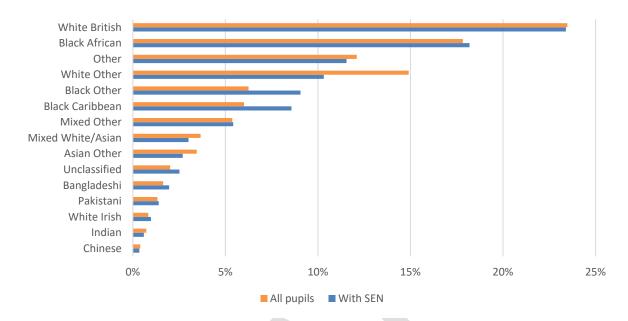
Source: School census, January 2017

# 3.3 Ethnicity

There are proportionately higher black other and black Caribbean pupils with SEN, compared to the school population as a whole.

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

<sup>&</sup>lt;sup>4</sup> System One and QOF data from Hammersmith & Fulham CCG



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

#### Source: School census, January 2017

#### 3.4 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 *er al.,* 2011: Parsons and Platt, 2013).

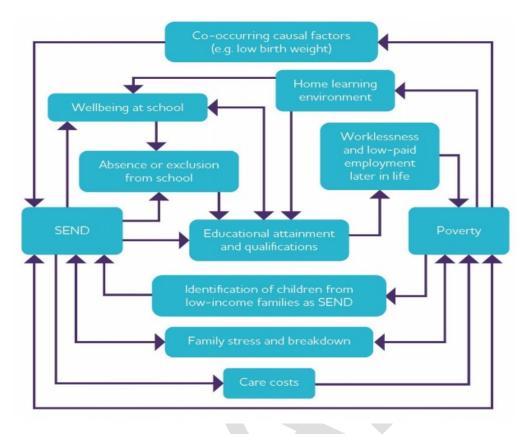
Hammersmith & Fulham is characterised by areas of high deprivation and areas of great wealth, with inequality of health outcomes. Children and young people with complex needs are more likely to live in deprived areas, in particular the north of the borough and areas of social housing.

<sup>&</sup>lt;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>&</sup>lt;sup>6</sup> <u>Special educational needs and their links to poverty</u>, Bart Shaw, Eleanor Bernardes, Anna Trethewey and Loic Menzies, 26th Feb 2016, Joseph Rowntree Foundation

<sup>&</sup>lt;sup>7</sup> Pasons 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





Source: Joseph Rowntree Foundation report, February 2016

# 4 Special educational needs in education

#### 4.1 Early years

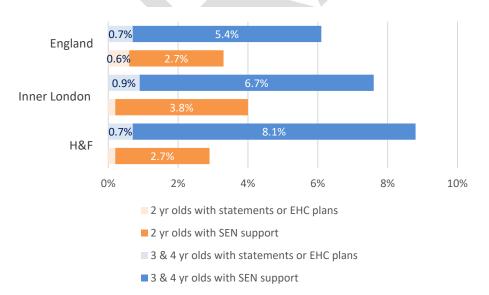
Early years education plays a pivotal role in both preventing SEN and preparing children who have SEND to be ready for school and therefore later educational attainment.<sup>8</sup>

#### 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 400 children aged 2 that are benefitting from funded early education in Hammersmith & Fulham. Of these, 0.2% have an EHC plan and 11 are receiving SEN support (2.7%). Hammersmith & Fulham is in line with the national average for 2 year olds with SEN support, both at 2.7%.

**3 & 4 year olds:** There are 3,900 children aged 3 and 4 that are benefitting from funded early education in Hammersmith & Fulham. Of these, 27 have an EHC plan (0.7%) and 316 are receiving SEN support (8.1%). Hammersmith & Fulham has a slightly higher percentage of 3 and 4 year olds receiving SEN support than the national average (8.1% vs 5.4% respectively).





Source: DfE Statistics - Provision for children under 5 years of age in England, 2017

<sup>&</sup>lt;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

#### 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 in line with the national average.

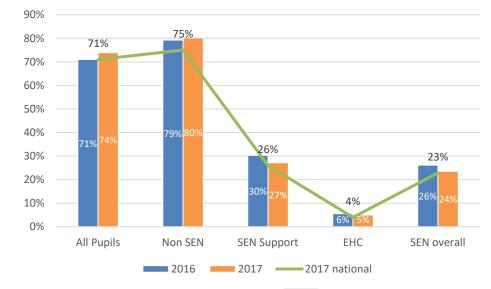
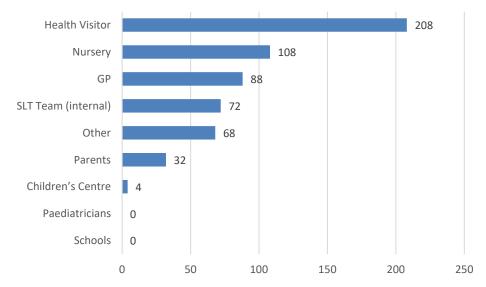


Figure 5: Percentage of early years' pupils reaching a good level of development



#### 4.1.3 Early years referrals for speech and language support

Speech and language support is the most likely need in early years. The majority of referrals for early years support in speech and language are made by health visitors (36% of referrals), followed by nursery schools (19% of referrals).





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

#### Professionals views on early years provision

Issues that have been identified locally at a professionals' workshop (see appendix 1) around early years provision as of particular concern by professionals from Children's services and health in Hammersmith & Fulham are:

- An understanding of the needs of children in independent nurseries
- Inequity in service provision such as speech and language therapy (SLT)
- Children who are home educated may not have had an assessment of their needs or the appropriate support put in place if they have not been seen by early years professionals
- There is a lack of pre-school provision for children with learning disabilities before they can be placed in a special school
- There is also a lack of pre-school support for children with autism in Hammersmith and Fulham

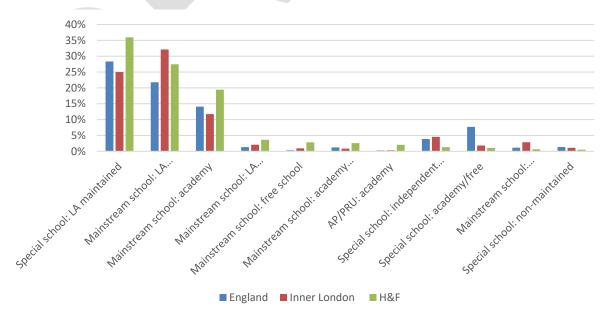
#### 4.2 Primary and secondary school years

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

#### 4.2.1 How many residents have SEND?

The number of children and young people who live in the borough and for whom the local authority maintains a statement of SEN, or an EHC plan is 776; 0.5% of children and young people with statements or EHC plans are educated elsewhere.

Of those maintained by the local authority, the majority of children and young people with a statement or EHC plan in Hammersmith & Fulham are educated in a special school (36%), a local authority maintained mainstream school (27%) or an academy (19%).





Source: Special educational needs and disability (SEND) and high needs (January 2017)

Within inner London there are high levels of borough migration for school. In 2017 in Hammersmith & Fulham there were:

- 14,902 pupils living in the borough, but 16,957 pupils attending schools maintained by the borough<sup>9</sup>.
  - 27% of pupils attending schools maintained by Hammersmith & Fulham live in a different borough.
  - 17% of pupils who live in Hammersmith & Fulham attend a school maintained by another borough.
- Hammersmith & Fulham is a net importer of pupils from other boroughs who attend its special school provision
  - Overall it is providing 189 places more for out of borough pupils than it uses elsewhere<sup>10</sup>
- In 2015 it was found that 25% of pupils who go to school in the borough, attend a private school<sup>11</sup>. These pupils are out of scope of the school data (DfE).

Therefore, unless otherwise stated, 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 Hammersmith & Fulham's spend on children and young people with <u>High Needs</u> was undertaken, which explains funding in detail, including pupils from outside the borough.

# 4.2.2 How many pupils have SEND?

In Hammersmith and Fulham 14.8% 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>12</sup>

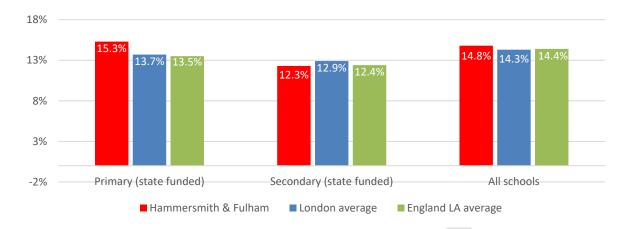
Hammersmith & Fulham (15.3%) has a slightly higher percentage of state funded primary school children receiving SEN support or with an EHC plan than London (13.8%) and England (13.4%)

<sup>&</sup>lt;sup>9</sup> <u>School pupils and their characteristics, January 2017: Table 13: Local Authority cross border movement by</u> national curriculum year group of state-funded school pupils resident in England

<sup>&</sup>lt;sup>10</sup> External review of Hammersmith & Fulham's spend on children and young people with high needs, 2017

<sup>&</sup>lt;sup>11</sup> GLA London Datastore: Schools and pupils, type, school, borough, 2015

<sup>&</sup>lt;sup>12</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



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 Hammersmith & Fulham has been consistent with the inner London average since 2010.
- > 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.

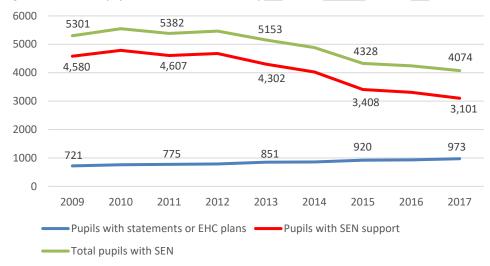


Figure 8: Number of pupils with a statement / EHC plan 2010-2017

Source: DfE SEN statistics

#### 4.2.4 Types of SEN needs locally

- Nearly half (43%) of state funded primary school pupils have speech, language and communication needs
- Nearly a third (29%) of state-funded secondary school pupils have a specific learning difficulty
- There are over 10% more state-funded secondary school pupils with a specific learning difficulty in Hammersmith & Fulham compared to the inner London average

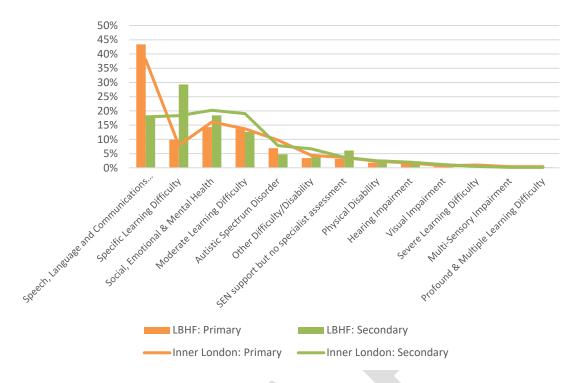
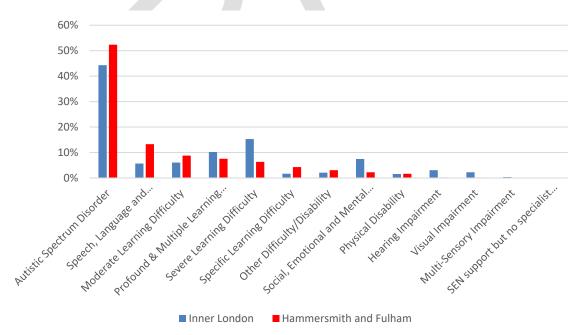


Figure 9: Percentage of state-funded primary and secondary school pupils with SEN, by primary need (2017)

#### Source: DfE Special Educational Needs, January 2017

Special schools in Hammersmith & Fulham have a higher percentage of pupils with speech, language and communication needs than inner London.

Figure 10: Percentage of state-funded special school pupils with SEN, by primary need



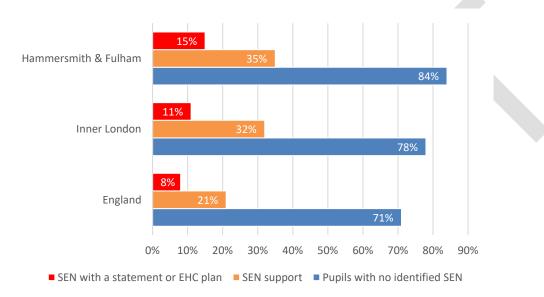
Source: DfE Special Educational Needs, January 2017

#### 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.

A higher percentage of H&F pupils with SEN are reaching the expected standard than compared with the national average

Figure 11: Percentage of pupils reaching the expected standard in reading, writing and mathematics at key stage 2 by SEN provision, 2017



Source: DfE Key Stage 2 statistics, September 2017

**<u>Attainment 8</u>** 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 receiving SEN support have a higher average attainment 8 score in Hammersmith & Fulham compared to inner London and England, but a lower score amongst pupils with a statement or plan.

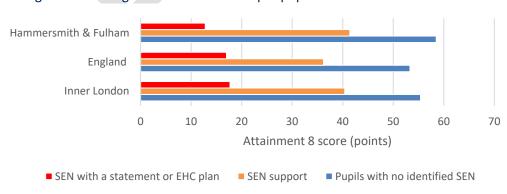


Figure 12: Average Attainment 8 score per pupil at KS4

Source: DfE - GCSE and equivalent attainment by pupil characteristics, January 2017

- There is a higher percentage of **persistent absentees** amongst pupils with SEN in Hammersmith & Fulham, inner London and England than the average for all pupils.
- Children with any form of SEN are significantly more likely to have at least one fixed term exclusion<sup>13</sup>

#### Professionals views on SEN provision in schools

A workshop with local professionals from Children's Services and health (see appendix 1) identified several issues with SEN provision in schools:

- There is inequity in services due to very different offers from schools, who buy and provide different services
- The offer is very different in mainstream schools compared to special schools, even with regards to school nursing which can be significant for certain children.
- There is a high amount of pressure on placements at special schools as there are so few.
- Home education is more likely to be considered by parents of children with challenging behaviour, such as children with autism, as the schools are unable to manage them. Home education can make it harder to ensure special needs are met adequately.
- There is wide variation in the amount of time Special Educational Needs Coordinators (SENCOs) have for giving SEN support, and other demands on their time are increasing, which is impacting on their time spent with children. A survey of SENCOs from the three boroughs in 2014 found that on average, 36% of a SENCO's time was being spent on managing SEND provision; 25% teaching or supporting pupils; 21% providing advice and training to staff. A further 18% of time was spent on other activities which are mainly administrative and managerial tasks.<sup>1</sup> Additionally, there is no longer a clearly allocated SEN budget in schools.
- The assessment process was identified as an issue, as it is lengthy and can leave children without the support they need whilst they wait.

#### 4.3 Transition years and outcomes post 16

#### 4.3.1 What do we know nationally?

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.

<sup>&</sup>lt;sup>13</sup> <u>DfE statistics SEN absences and exclusions</u>

Participation in education or training is important for young people's outcomes, but Ofsted have reported insufficient transition arrangements for people with SEND<sup>14 15</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. <u>Guidance for institutions</u> 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.

#### 4.3.2 What do we know locally?

As of June 2017, Hammersmith & Fulham has slightly higher participation in education or training amongst the SEND cohort than the London and national average (97% of SEND cohort in education or training)

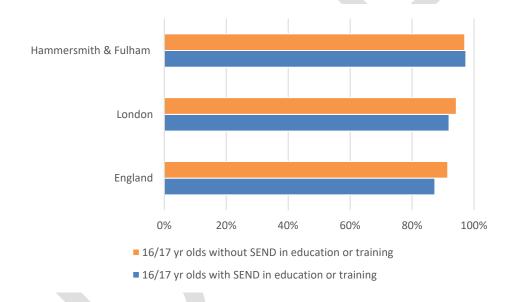


Figure 13: Proportion of 16-17 year olds recorded in education and training by SEND, June 2017

# Source: DfE Participation in Education and Training figures, 2017

# 4.3.3 Post-16 Provision

The <u>Local Offer</u> details the support available for education, employment and training. The external review of the borough's spending on high needs stated that 'with increased national expectations around entitlement to post 16 education, there is a probability that more parents will ask for their children to stay on in independent/ non-maintained provision, and this could involve significant increase in cost (with no increase in the money that Government has made available).'<sup>16</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>&</sup>lt;sup>14</sup> Progression post-16 for learners with learning difficulties and/or disabilities, Ofsted survey, 2012

<sup>&</sup>lt;sup>15</sup> <u>Moving forward</u>? How well the further education and skills sector is preparing young people with high needs for adult life, Ofsted, 2016

<sup>&</sup>lt;sup>16</sup> An external review of Hammersmith and Fulham's spending on high needs

#### Professionals views on SEN in post 16 settings

A workshop with local professionals (see appendix 1) identified several issues around SEN in post-16 settings.

- Transitions:
  - Transition points were flagged by practitioners as a time when individuals fall through the net.
  - One reason for this is that post 16, young people self-identify as having SEND, which can result in under-reporting.
  - The needs of young people with SEND who will not be eligible for Adult Social Care are of particular concern, as support thresholds are higher for adults than children.
  - o Transition post-children's health services to adult services and primary care
  - There is a lack of joined up conversations between services which leads to a lack of understanding about other service's scope and agenda. This is particularly an issue during transition.
  - Some schools are much better than others at signposting young people and parents to appropriate courses for post-16 education. The colleges themselves are good, but it is not clear what the Local Authorities should fund and what is most appropriate for young people with particular SEND.

#### Colleges

- Therapy interventions in colleges and other post-16 settings was identified as an issue. Schools and colleges are struggling with people with learning disabilities without EHCPs.
- The workforce in further education colleges and post-16 settings require upskilling in working with people with complex needs
- Preparation for adulthood
  - SEN support post 16 gap particularly independent living skills. Post-16 students in schools needing independent living skills delivery. There is a question about where this is best provided.
  - Transition around employment e.g. apprenticeships have high impact rates.
     Transitions cohort (employment) due to be addressed in the Children's / ASC supported employment strategy
  - Each borough has a supported employment service in place, and for cohorts going through transitions work needs to be done in an education setting to raise expectations from young people and their parents about their ability to work.

# 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>17</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

#### 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>18</sup> Educational settings, parents or young people 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.

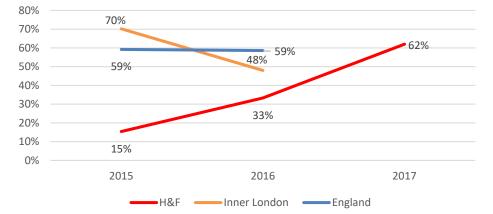
#### **EHC Plan assessments**

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

Regulations set out that the overall time it takes from the local authority receiving a request for an assessment and the final EHC plan being issued (if one is required) should be no longer than 20 weeks. In 2016, only 33% of assessments in Hammersmith & Fulham were conducted within the statutory time of 20 weeks, however, this increased to 62% in 2017.

<sup>&</sup>lt;sup>17</sup> NHS Choices: Special Educational Needs

<sup>&</sup>lt;sup>18</sup> NHS Choices: Special Educational Needs



#### Figure 14: Percentage of new EHC plans issued within 20 weeks in Hammersmith & Fulham

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

#### Conducting an Education, Health and Care Needs Assessment flowchart

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 Hammersmith & Fulham are educated in a special school, a mainstream school or an academy.

#### 5.2 Diagnosing complex needs

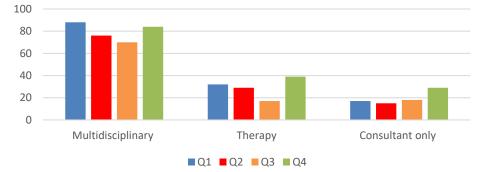
Where needs are more complex, health professionals including the Child Development Service in the local NHS trusts may undertake the assessment and diagnosis.

In Hammersmith & Fulham, the Child Development Service is provided by the Chelsea & Westminster Hospital NHS Trust Child Development and Neurodisability 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.

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

- There were 645 referrals from Hammersmith & Fulham to the Cheyne Child Development Service in 2017/18
- Most referrals in Hammersmith & Fulham require appointments with a multi-disciplinary team, the most resource intensive type of appointment.

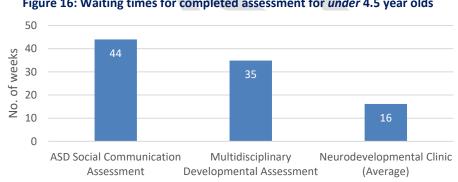


#### Figure 15: Referrals from H&F to the Cheyne Child Development Service by appointment type

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

#### 5.2.2 Waiting time in Hammersmith & Fulham

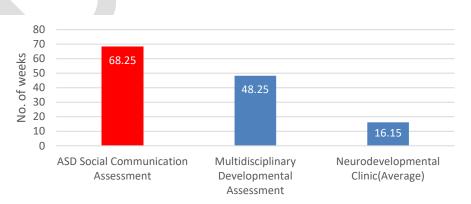
- NICE guidelines state that an autism diagnostic assessment should start within three months of the referral to the autism team<sup>19</sup>.
- > Average waiting times for referral to diagnosis of ASD for 4.5 year olds and older was, on average, longer than a year in 2017/18.
- > NB. This is the average waiting for the service, which includes referrals from parts of Westminster, Kensington and Chelsea and Hammersmith & Fulham



#### Figure 16: Waiting times for completed assessment for under 4.5 year olds



#### Figure 17: Waiting times for completed assessment for over 4.5 year olds

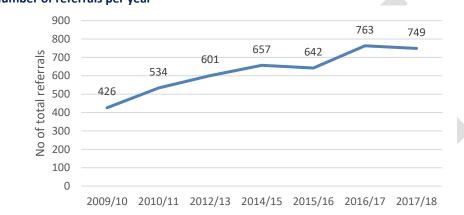


Source: Chelsea and Westminster NHS Trust Child Development Service, 2017/18

<sup>&</sup>lt;sup>19</sup> National Institute for Health and Care Excellence: Autism spectrum disorder in under 19s: recognition, referral and diagnosis

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 18: Number of referrals per year

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

#### Types of special educational needs and disabilities in detail

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

#### 6 Speech, language and communication needs

#### 6.1 Definition

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>20</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>21</sup>

#### 6.2 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>22</sup>.

Language skills are linked to academic success and positive self esteem<sup>23</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>24</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>25</sup>.

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

#### 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.

<sup>&</sup>lt;sup>20</sup> (I CAN, 2006)

<sup>&</sup>lt;sup>21</sup> <u>I CAN</u>, accessed 2017

<sup>22 (</sup>Lindsay & Dockrell, 2012)

<sup>&</sup>lt;sup>23</sup> (I CAN, 2006)

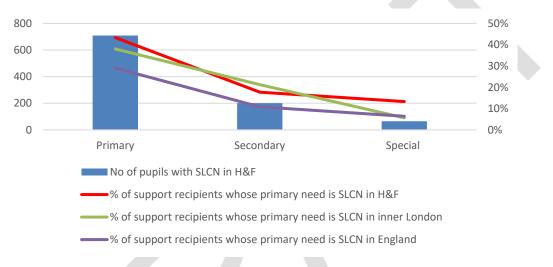
<sup>&</sup>lt;sup>24</sup> (Public Health England & the UCL Institute of Health Equity, 2014)

<sup>&</sup>lt;sup>25</sup> (Public Health England, 2016)

#### 6.3 What do we know locally?

- In Hammersmith & Fulham, there are 975 pupils receiving SLCN support from Central London Community Health's Speech and Language therapy service(30% of all pupils with SEN) and it is the most common reason for SEN support among primary school pupils.
- There were 615 referrals to the Early Years SLT team in 2017/18. Please see Early Years section above for more information.
- Hammersmith & Fulham 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

Figure 19: 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

> Hammersmith & Fulham has a lower percentage of children with SLCN amongst children receiving support, than inner London.

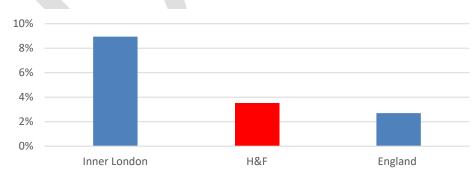


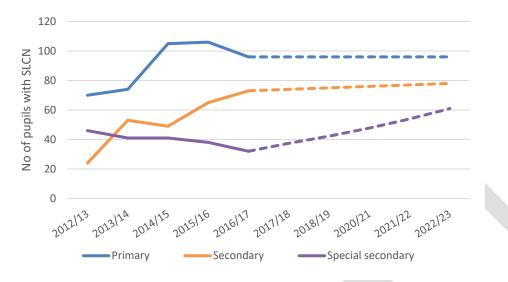
Figure 20: Percentage of all pupils with SLCN as their primary need

#### 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 <u>guidance to Health & Wellbeing</u> <u>Boards</u> suggests that as many as 10% of children may have some form of SLCN. This suggests that some children who need support may not be receiving it.

#### 6.3.1 Future trends

Based on 2013 to 2017 trends, it is predicted that there could be an increase in numbers of pupils with SLCN in secondary and special schools:



#### 6.4 What works?

In response to the Children & Families Act, the Royal College of Speech & Language Therapists published <u>guidance for speech and language therapists</u> (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.

<sup>&</sup>lt;sup>26</sup> (I CAN, 2008)

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
- 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

<sup>&</sup>lt;sup>27</sup> (Gross, 2011)

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.

#### 1.1.1 Case Study: Hartlepool

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

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

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

#### **Professionals view**

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

<sup>&</sup>lt;sup>28</sup> (Gascoigne, 2012)

# 7 Social, Emotional and Mental Health (SEMH)

#### 7.1 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>

#### 7.2 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 condition32
- 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>

#### 7.3 What do we know locally?

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

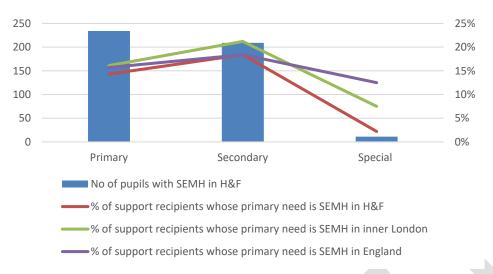
<sup>&</sup>lt;sup>29</sup> Royal College of Speech and Language Therapists

<sup>&</sup>lt;sup>30</sup> Royal College of Speech and Language Therapists

<sup>&</sup>lt;sup>31</sup> <u>SEN Code of Practice</u>

<sup>&</sup>lt;sup>32</sup> Department of Education, 2016

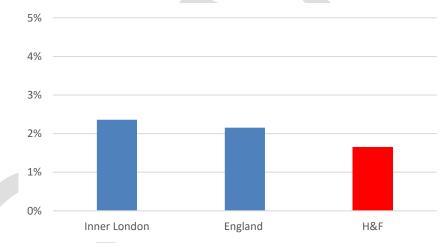
<sup>&</sup>lt;sup>33</sup> <u>NICE, 2008</u>



#### Figure 21: 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, January 2017

Hammersmith & Fulham has similar percentages of pupils receiving support for social, emotional and mental health



#### Figure 22: 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

#### **Care, Education and Treatment Reviews**

Care, Education and Treatment Reviews CETRs are focused on those children and young people who either have been, or may be about to be admitted to a specialist mental health / learning disability hospital either in the NHS or in the independent sector. CETRs bring together those responsible for commissioning and providing services (this will include nurses, social workers, education, commissioners and other health, education and social care professionals alongside strategic commissioners where appropriate) with independent clinical opinion and the lived experience of children and young people and families from diverse communities with learning disabilities, autism or both. CETRs are driven by the NHS but the involvement of local authorities and education services in the CETR process and its outcomes is integral to improving care, education and treatment for children and young people with learning disabilities, autism or both and their families.

#### 7.4 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

# ENGAGE THE WHOLE COMMUNITY

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

difficulties whose families may feel blamed and stigmatised

#### Prioritise professional learning and staff levelopment

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

# Adopt wholeschool thinking

Use a 'whole school approach', which ensures that all parts of the school organisation work coherently together
Provide a solid base of positive universal work to promote well-

being and help prevent problems Develop a supportive school and classroom climate and ethos which builds a sense of connectedness, focus and purpose, the acceptance of emotion, respect, warm, relationships and communication and the celebration of difference

 Start early with skills based programmes, preventive work, the identification of difficulties and targeted interventions. Work intensively, coherently, and carry on for the long term
 Promote staff well-being, and particularly

address staff stress levels

#### Develop supportive policy

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

#### Implement targeted programmes and interventions (including curriculum)

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

#### Implement targeted responses and identify specialist pathways

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

#### Connect appropriately with approaches to behaviour management

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

# **Source:** <u>National Children's Bureau: Framework for promoting well-being and responding to mental</u> <u>health in schools</u>

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.

#### 1.1.2 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

# 8 Specific Learning Difficulties

#### 8.1 Background

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

#### 8.2 What do we know nationally?

- The British Dyslexia Association <u>estimates</u> 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).

#### 8.2.1 Prevalence by demography

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

#### 8.2.2 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>.

<sup>&</sup>lt;sup>34</sup> (Eissa, 2010)

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

- ADHD is associated with higher rates of job termination and lower performance ratings, poorer family relationships; higher rates of physical injury (20.4% vs 11.5%). substance misuse and sexual risk, and a slightly higher suicide rate<sup>36</sup>
- 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>.

#### 8.3 What do we know locally?

515 pupils in Hammersmith & Fulham are receiving SEN support primarily for specific learning difficulties, as of January 2017. (1.5% of primary pupils, 3.6% of secondary pupils, and 4.7% of special school pupils)

The proportion of all pupils in each type of school that have a specific learning difficulty compared to inner London is shown here:





#### Sources: DfE - Special Educational Needs and School and pupil numbers, January 2017

Since 2010, when the data was first published, Hammersmith & Fulham has had consistently slightly higher percentage of its pupils receiving support for specific learning difficulties than the other boroughs and the regional/national averages.







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

<sup>&</sup>lt;sup>37</sup> (Caçola, 2016)

#### 8.4 What works?

A 2012 report**38** 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.

<sup>&</sup>lt;sup>38</sup> (Dyslexia Action, 2012)

<sup>&</sup>lt;sup>39</sup> (Dylsexia Action, 2013)

<sup>&</sup>lt;sup>40</sup> (Brooks, 2016)

Schemes for improving writing are few, and Grammar for Writing has great potential.	Provided they receive continuing support, children who make these gains should be better able to cope with the secondary curriculum.	
Schemes for children who struggle with spelling work best when highly structured.	Children with spelling problems need schemes tailored to their preferred ways of learning and delivered systematically 'little and often'. Such schemes work particularly well for enabling children to grasp relatively regular patterns of spelling.	
Work on phonological skills for reading should be embedded within a broad approach.	Phonics teaching should normally be accompanied by graphic representation and reading for meaning so that irregular as well as regular patterns can be grasped. Children with severe difficulties in phonological skills, or using English as an additional language, may need more 'stand-alone' phonics teaching to support their speaking and listening.	
Children's comprehension skills can be improved if directly targeted.	Engaging the child in exploring meaning embeds the relevance of reading for life, expands vocabulary and broadens the range of texts. Children falling behind their peers need both carefully structured reading material and rich, exciting texts.	
ICT approaches work best when they are precisely targeted.	The mediation of a skilled adult is essential to ensure technologically driven schemes meet children's needs. Time needs to be allocated effectively so that the diagnostic tools of programmes can be used for each child appropriately.	
Large-scale schemes, though expensive, can give good value for money.	When establishing value for money, long-term impact and savings in future budgets for special needs must be considered, particularly when helping the lowest-attaining children.	
Where Teaching Assistants can be given appropriate training and support, they can be very effective.	TAs need skilled training and support to maximise impact. A school needs to manage them so that feedback to classroom teachers is effectively and regularly given.	
Good impact – sufficient to at least double the standard rate of progress – can be achieved, and it is reasonable to expect it.	If the scheme matches the child's needs, teachers and children should expect to achieve rapid improvement. High expectations are realistic expectations in most cases.	

# 9 Learning disabilities

#### 9.1 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>.

#### 9.2 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

#### 9.2.1 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:

<sup>&</sup>lt;sup>41</sup> (Prasher & Routhu, 2016)

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

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

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

Source: DfE Statistics: Special Educational Needs

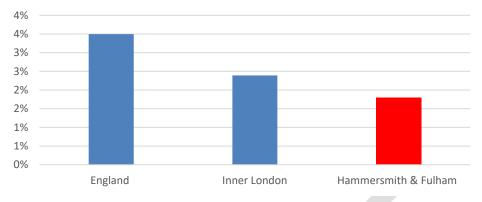
• Free School Meals: All children with SEN are almost twice as likely to be claiming free school meals as the general school population (27.2% vs 14.3%). It is even more likely in children with LD: 30.4% are eligible. This is the second highest proportion after Social, Emotional & Mental Health Needs.

#### 9.3 What do we know locally?

- There are **176 children and young people** aged 0-25 with learning disabilities known to GPs within the Hammersmith & Fulham clinical commissioning group (November 2017), 0.3% of the CCG 0-25 population.
- **Gender:** 66% male and 34% female
- > Social care:
  - Learning disabilities is the third highest proportion of social care cases in Hammersmith & Fulham amongst children in need aged 0-17.
  - 38% of social care cases for young people aged 18-25 are for learning disabilities support
- Co-occurring conditions: Learning disabilities co-occurs with mental health disorders and autism, as well as other conditions such as Rhetts, Down Syndrome, Prader-Willi etc.
- In 2014/15 Hammersmith & Fulham had the sixth lowest recorded prevalence for learning disabilities in London.
- In 2017 Hammersmith & Fulham has similar percentages of pupils with learning disabilities as inner London, both of which have a smaller proportion than England overall.
- Health Checks :

People with learning disabilities (LD) have poorer physical and mental health than other people and die younger. Many of these deaths are avoidable and not inevitable. Annual health checks and health action plans are available from GP practices to all those on the practice learning disability register aged 14 and over. Health checks aim to identify undetected health conditions early, ensure the appropriateness of ongoing treatments and establish trust and continuity of care.

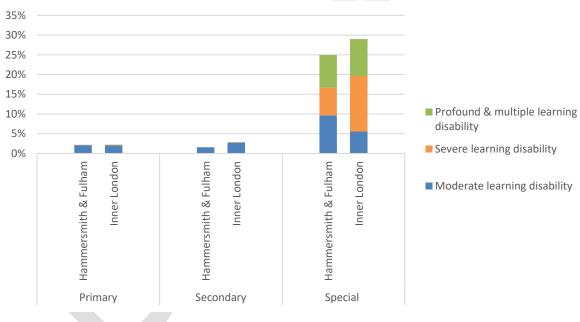
In H&F there are 116 young people aged 14-25 on their GP Practice LD register. 75 % (87bCYP) received an annual health check in 2017/18.



#### Figure 25: 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.

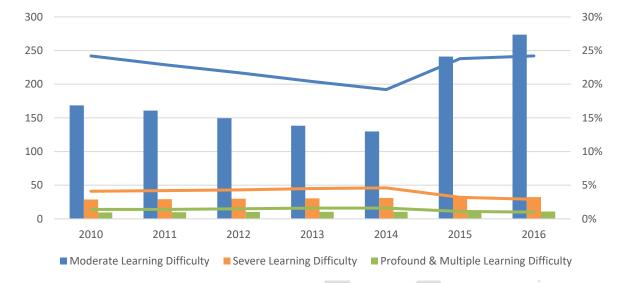


This is similar to inner London proportions Figure 26: Percentage of pupils in each school with learning disability by type



# 9.3.1 Trends

Since 2015, children receiving support for SEN are also counted in these statistics; previously, only children with School Action, School Action Plus or statements of SEN were included. Hence, numbers from 2015 onwards are not comparable. However, it is noticeable that between 2010 and 2014, the proportion of children identified as having LD fell from almost 30% to just over 25%. 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 27: 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.* 



#### 9.4 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. 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.

The Learning Disability 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

Further information of the six good practice initiatives identified please see -

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/261896/Learning\_ Diasbilities\_Good\_Practice\_Project\_November\_2013\_.pdf

#### 9.4.1 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.

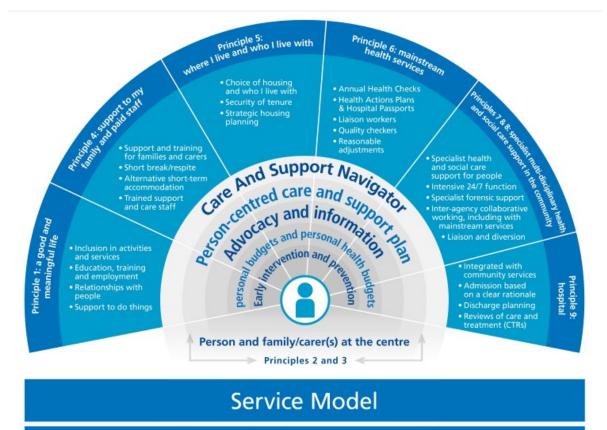


Figure 28: Service model for people with a learning disability who display behaviour that challenges.

Commissioners understand their local population now and in the future

#### 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.

## 10 Autism

## 10.1 Background

Autistic spectrum disorder (ASD) is defined by the <u>NHS</u> 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).

## 10.2 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>44</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>45</sup>

## 10.3 What do we know locally?

- There are 527 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: 80% male and 20% female, this imbalance is in line with the national prevalence rate

The number of pupils who go to school in the borough with autistic spectrum disorder:

- 113 in primary school (6.9% of children with SEN, slightly below the inner London average of 9.7%)
- 54 in secondary school (4.8% of children with SEN, slightly below the inner London average 6.9%)
- 256 in special primary and secondary schools (52.4% of children with SEN, slightly higher than the inner London average at 44.3%)<sup>46</sup>

<sup>44 (</sup>Schieve, et al., 2012)

<sup>&</sup>lt;sup>45</sup> (Office for National Statistics, 2009)

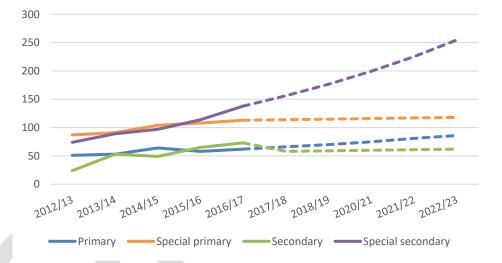
<sup>&</sup>lt;sup>46</sup> DfE Special Educational Needs, January 2017

## 10.3.1 Future trends

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

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

Using the GLA pupil roll projections for pupils who live in the borough, and percentage increase between 2013 and 2017, projections suggest numbers of children with ASD who both go to school *and* live in the borough will increase. 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 29: Projected increase in numbers of children who go to school and live in Hammersmith & Fulham

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.

### 10.4 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>47</sup>.

ASD and its sequale are complex hence there are a range of educational and behavioural programmes for children with ASD. The National Autistic Society outlines the various strategies and

<sup>&</sup>lt;sup>47</sup> NICE Autism spectrum disorder in under 19s: support and management

approaches to managing children with ASD, but there are four key themes that are incorporated in these approaches:

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

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

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

## Families and service user views

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

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

### 1.1.3 Professionals views

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

## 11 **Physical Disabilities**

## 11.1 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>48</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.

A 2016 report by The Council for Disabled Children<sup>49</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>50</sup>

## 11.2 What do we know nationally?

- 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 nondisabled 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.

<sup>&</sup>lt;sup>48</sup> <u>Understanding the needs of disabled children with complex needs or life-limiting conditions</u>

What can we learn from national data? Anne Pinney, Council for Disabled Children, 2016 <sup>49</sup> Council for disabled children report

<sup>&</sup>lt;sup>50</sup> .(From <u>council for disabled children</u>) 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

## 11.3 What do we know locally?

## **11.3.1** Disabilities and education

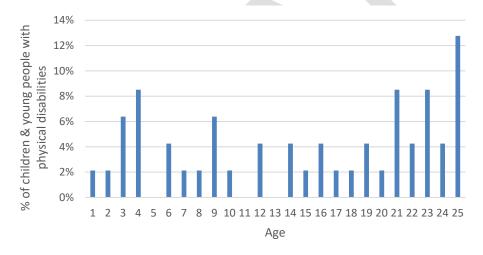
Not all children who are defined as disabled will have Special Educational Needs (SEN). The Disability Equality Duty sets out a general duty to promote disability equality, and a specific duty, which applies to schools, and includes a requirement to publish a Disability Equality Scheme.

Schools will be making a wide range of reasonable adjustments for individual disabled pupils, as well as in their practices, procedures and policies, but may also need extra support from us in particular circumstances such as with very specialised equipment

Some children with disabilities are supported by the SEN framework in schools. For support outside schools, the disabled children's team provide information and support.<sup>51</sup>

- There are 47 children and young people aged 0-25 registered with a GP in the Hammersmith & Fulham CCG boundary with physical disabilities, 0.1% of the CCG 0-25 population
- Gender: 55% male and 45% female)
- > Co-occurring conditions: 43% have a co-occurring condition of mental health

Figure 30: Percentage of children and young people with physical disabilities by age



Source: System One and QOF data, Hammersmith & Fulham CCG, as at November 2017

As of January 2017 3.4% of all primary school pupils with SEN, 6.7% of secondary pupils with SEN, and 1.6% of special school pupils had physical disabilities as their primary need in Hammersmith & Fulham

Figure 31: Percentage of all pupils with SEN, whose primary need is physical disabilities

<sup>&</sup>lt;sup>51</sup> Hammersmith & Fulham: special educational needs and disabilities webpage



### Source: DfE Special educational needs in England: January 2017

### Hammersmith & Fulham Disabled People's Commission: 'Nothing about us without us'

In November 2017 a report was published from the Hammersmith & Fulham Disabled People's Commission. The council made a commitment to working closely with Disabled residents to make decisions about support and services.

In the foreword the Chair of the Commission, Tara Flood, explained the current disabled people's health and life outcomes:

"For many Disabled people life remains, or is increasingly becoming, a complex experience of segregation from our non-Disabled peers. We experience limited life choices and opportunities, unmet personal and social care needs, isolation, unemployment, unsuitable housing, persistent poverty, abuse, and violence."

### 11.4 Sensory impairments

### 11.4.1 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 167 children and young people aged 0-25 with a visual impairment known to their GP in the CCG boundary, 0.3% of the CCG 0-25 population
- Gender: 51% male and 49% female
- > 4% of social care cases of the Children's Disability Team are for visual impairment
- 0.8% of primary pupils with SEN, 1.5% of secondary pupils with SEN, and 0.2% of special school pupils with SEN have visual impairment as their primary need

Figure 32: Percentage of all pupils with SEN, whose primary need is visual impairment



Source: DfE Special educational needs in England: January 2017

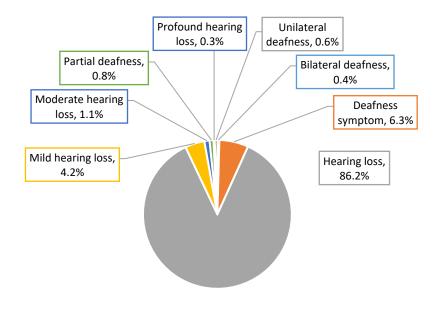
### 11.4.2 Hearing impairment

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 710 children and young people aged 0-25 with a hearing impairment known to their GP within the CCG boundary, 1% of the CCG 0-25 population
- Gender: 51% male and 49% female
- > 1% of social care cases of the Children's Disability Team are for hearing I impairment
- Majority of children and young people with a hearing impairment have hearing loss, with small percentages with profound hearing loss and deafness.

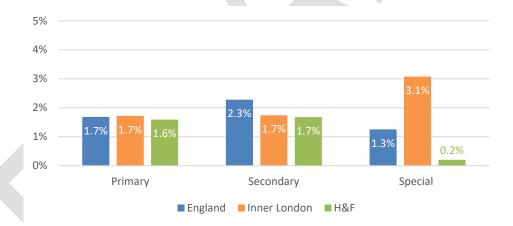
Figure 33: Proportion of children and young people with hearing impairment by level of impairment



## Source: System One and QOF data, Hammersmith & Fulham CCG, as at November 2017

1.6% of primary pupils with SEN, 1.7% of secondary pupils with SEN, and 0.2% of special school pupils with SEN have hearing impairment as their primary need



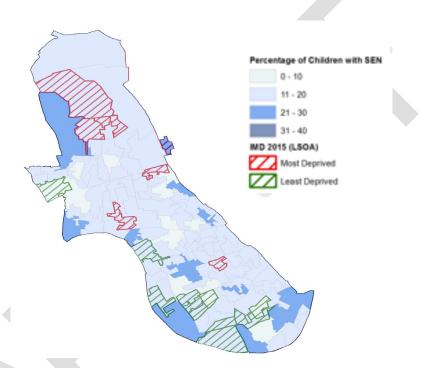


### Source: DfE Special educational needs in England: January 2017

## 12 Long term health conditions

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

Figure 35: Children with health specific special educational needs and disabilities, cross referenced with most and least deprived areas



### Source: System one and QOF data, Hammersmith & Fulham CCG, November 2017 and Index of Deprivation 2015

Asthma, type 1 diabetes and epilepsy are the most common long-term physical health conditions in children. The majority of children diagnosed with these conditions will have their needs met in schools in line with the "Supporting Children with Medical Conditions at Schools" Dfe Guidance, Sept 2014). They will not require special educational provision and therefore should not viewed as cyp with SEND. However, in some instances there may be an overlap between students with SEN and students with a medical condition or the severity and complexity of the child's long term condition meant that they may be considered disabled under the Equalities Act, 2010 and may require special educational provision.

Very few children with long term health conditions live in the most deprived or least deprived areas of Hammersmith & Fulham.

### 12.1 Asthma

Of all children and young people aged 0-25 registered with a GP within the clinical commissioning group boundary, there are 2,068 children and young recorded as having asthma, 4% of the CCG 0-25 population (53% male and 47% female).

Pollution can trigger asthma symptoms and all inner London boroughs, including Hammersmith & Fulham, 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.

## 12.2 Diabetes

- Of all children and young people aged 0-25 registered with a GP within the clinical commissioning group boundary, there are **193 children and young people** recorded as having diabetes (47% male and 53% 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>.

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

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

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

## 12.3 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>

<sup>&</sup>lt;sup>52</sup> Diabetes UK: <u>https://www.diabetes.org.uk/About\_us/News\_Landing\_Page/UK-has-worlds-5th-highest-rate-of-Type-1-diabetes-in-children/List-of-countries-by-incidence-of-Type-1-diabetes-ages-0-to-14/</u>

<sup>&</sup>lt;sup>53</sup> Diabetes UK: <u>https://www.diabetes.org.uk/Guide-to-diabetes/Your-child-and-diabetes/Schools/School-staff/Responsibilities-SENCOs-Additional-Needs-Coordinators-Inclusion-Managers/</u>

<sup>&</sup>lt;sup>54</sup> Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council of the UK and Ireland, September 2011

## **12.4 Children's Continuing Care Packages / Continuing Healthcare**

Some children and young people (up to their 18th birthday), may have very complex health needs. These may be the result of congenital conditions, long-term or lifelimiting or life-threatening conditions, disability, or the after-effects of serious illness or injury. These needs may be so complex, that they cannot be met by the services which are routinely available from GP practices, hospitals or in the community commissioned by clinical commissioning groups (CCGs) or NHS England. A package of additional health support may be needed. This additional package of care has come to be known as continuing care. Continuing care is not needed by children or young people whose needs can be met appropriately through existing universal or specialist services through a case management approach. The national framework for Children and Young People's Continuing Care covers young people up to their 18th birthday. Thereafter, the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care apply.

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>55</sup>

Personal health budgets can be used where requested by the child or their family.

### What do we know locally?

In September 2018 there were 25 children and young people registered with H&F GPs in receipt of Children's Continuing Care packages and X young people aged 18 to 25 in receipt of NHS Continuing Healthcare.

<sup>&</sup>lt;sup>55</sup> National Framework for Children and Young People's Continuing Care, 2016, Department of Health

# 13 Social Care

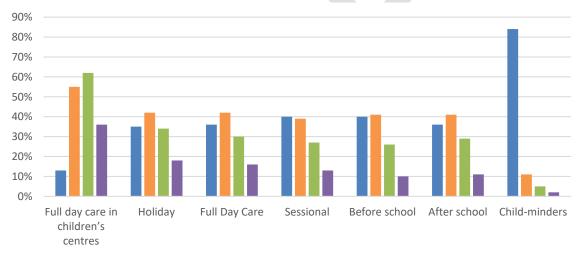
## 13.1 Background

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.

## 13.2 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.



### Figure 36: Proportion of providers caring for children with disabilities, 2013

Do not currently care for children with disabilities Care for children with minor disabilities

Care for children with moderate disabilities

Care for children with severe disabilities

## 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

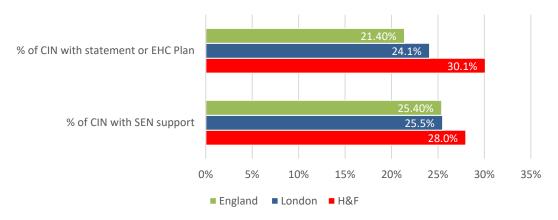
12% of primary schools are attended by children with severe disabilities compared to 49% of nurseries. What do we know locally?

### 13.2.1 Children in need

In Hammersmith & Fulham, 22.7% of children in need are receiving SEN support and 28% of children in need have a statement of SEN or EHC plan.<sup>56</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.

<sup>&</sup>lt;sup>56</sup> Local Government Association Local area SEND report

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.



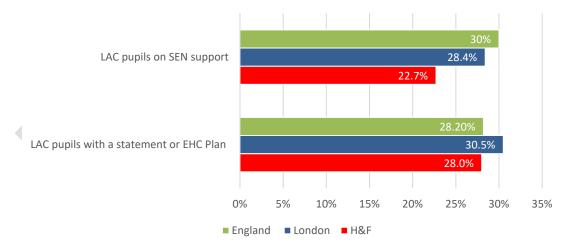




### 13.2.2 Looked after children

Looked after children are defined as those looked after by the local authority for one day or more. In Hammersmith & Fulham, 22.7% of looked after children are on SEN support, compared to 28.4% in London. There are 28% of looked after children in Hammersmith & Fulham that have a statement of SEN or EHCP, compared to 30.5% in London.





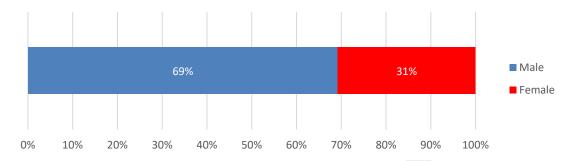
Source: Department for Education, Outcomes for Children Looked After by Local Authorities in England

### 13.2.3 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 206 children in need in 2015/16 and 245 in 2016/17. As of September 2017/18, the team were working with 203 children in need. As at 31<sup>st</sup> March 2017, there were more boys than girls receiving social care support from the Disabled Children's Team.

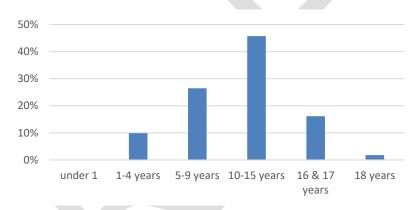




Source: Hammersmith & Fulham's Children's Services Business Intelligence, November 2017

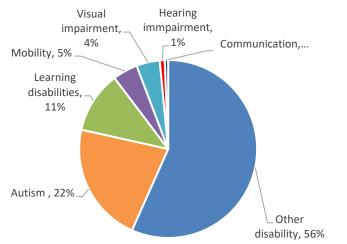
The largest proportion of children receiving support from the Disabled Children's team are 10-15 year olds

Figure 40: Proportion of children in need receiving support from the Children's Disabled Team, by age as at 31<sup>st</sup> March 2017



Source: Hammersmith & Fulham's Children's Services Business Intelligence, November 2017

#### Figure 41: Proportion of social care cases in Hammersmith & Fulham by type as at 31st March 2017



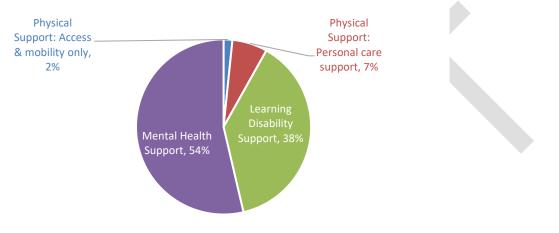
Source: Hammersmith & Fulham's Children's Services Business Intelligence, November 2017

## 13.2.4 Care needs of young people age 18-25

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

Over half of the young people aged 18-25 receiving social care support are receiving support for mental health, the second largest support reason is learning disabilities

Figure 42: Proportion of young people aged 18-25 receiving social care support in Hammersmith & Fulham by primary support reason



Source: Short and Long Term Support Return - LTS001b Long Term Support at year end (31st March 2017) by Primary Support Reason

# 14 Parents and carers of children with complex needs

## 14.1 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 (Twoy 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.

## 14.2 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 <u>SEND Local Offer</u>. 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"

A summary of these issues raised in Parent Forum Focus Groups is included in the appendices. Focus Groups were held on: Early Years; Mainstream provision; Specialist provision; Short Breaks; Post 16; and Health and Therapies.

## 14.3 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

Across studies, there was a wide variety of designs, outcomes and measures used, and there was no conclusive evidence on which intervention was most effective. The authors conclude that multiple

interventions may be effective in reducing burdens of care experienced by families of children with complex needs.

### 15 **Bibliography**

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## 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 2017 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.

## 17.2 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 Hammersmith and Fulham 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 Hammersmith & Fulham'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.

### 16.2 Appendix 3 – NICE Guidelines

- Transition from children's to adults' services for young people using health or social care services
- <u>Autism spectrum disorder in under 19s: support and management</u>
- 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
- <u>Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges</u>

### 16.3 Key guidance

The government sets out a <u>range of guidance materials</u> for schools, colleges and children's services in providing for children and young people with SEND. This is encapsulated in the <u>SEND Code Of Practice for 0 to</u> <u>25 years</u>, 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 <u>Early Years guide</u> and <u>statutory framework</u>.

<u>NICE</u> provides a number of relevant clinical guidelines and guidance documents which can be found in the appendices.

Other relevant projects, for example 'Children and young people with disabilities and severe complex needs: social care support', are currently in development.

The <u>Learning Disability Transition Pathway Competency Framework</u> 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.

Ea	Early Years		2. Mainstream		3. EHCNA Process		4. Health /		5. Social Care		6. Post 16		7. Training	
						Th	erapies	Pr	ovision					
a.	Lack if inclusion in early year settings. Examples of parents informed that child must have an EHCP to access certain settings	a.	Schools should be held to account around the "mainstream school local offer"? Schools need	a.	would like regular updates on number of EHC transfers completed and ongoing timetable for completingtransfers	a. b.	Waiting times for appointments remains a significant concern. More clarity as to what parents	a.	Social Work Assessments are not always read or understood by parents and need to be simplified Need some QA and	a.	How do colleges access specialist services such as Educational Psychology and Therapies? More work needs	a.	Training of professionals in nurseries/schools and colleges re supporting children and young people with complex medical is	
ي Page 98	Examples of Nurseries not supporting families	challenging aro communicating that, for examp	challenging around communicating that, for example, needs cannot be	b. Parents shou			should expect around SALT as their child progresses	5.	monitoring of Short Breaks Offer – choice is limited and turnover of	<i>b</i> .	to be done in improving the FE Colleges Local Offer and clarifying	e	essential	
	to make a request for an EHC Plan insufficient information.		met when child is not toilet trained or requires medical		of Key Workers at first available opportunity.		through school and on into college.		staff is another significant issue	с.	pathways in FE.	5.	around working with parents - there are times when parents	
	information.	c.	support Parents Forums are seeing a good number of "informal" exclusions and are concerned about	c.	Examples of information not shared or handed from one Key Worker to another – processes need to be improved to	c.	If therapies are delivered out of school premises – needs to be communicated as to whose responsibility is to	c.	Would a questionnaire be helpful to gain the views of gain families experience as to quality of		support and training around the post 16 Local Offer and importance of Yr. 9 Review.		experience hostility in the face of challenge, as opposed to empathy and support	

# 16.4 Appendix 5- Summary of issues raised in Parent Forum Focus Groups

Early Years	2. Mainstream	3. EHCNA Process	4. Health / Therapies	5. Social Care Provision	6. Post 16	7. Training
<ul> <li>c. Educational Psychologists not involved with children under 5 years old – hence for those with unidentified medical needs, examples of requests for EHC Plans being rejected.</li> <li>d. Transparency required around targeted SEN funding for Early Years settings.</li> <li>e. Transparency around effectiveness of</li> </ul>	<ul> <li>this – what is the data saying around exclusions?</li> <li>d. Local Offer website needs to be very clear as to what Direct Payments fund and don't fund.</li> <li>e. SEN Information Reports need to be improved – some say very little and not clear what support is offered.</li> <li>f. Communication between home and school needs improving and</li> </ul>	<ul> <li>avoid unnecessary delays</li> <li>d. Parents are asked to communicate by emails but these are not always responded to in a timely manner</li> <li>e. Assessments are still taking much too long – Parent Forums would like to work with SEN Service to communicate updates and improvements to parents</li> </ul>	<ul> <li>take the child to the therapy during school hours.</li> <li>d. More clarity required as to children with SEND in early years' settings having equal access to therapies across the borough, regardless of their setting.</li> <li>e. More training is needed around giving a diagnosis – Parent Forums can support this work.</li> </ul>	<ul> <li>short breaks provision?</li> <li>d. Social Workers don't always understand the currency and legal status of the EHC Plan - more workforce activity required</li> <li>e. Short breaks and after school clubs can be difficult to access due to transport timetables</li> </ul>	<ul> <li>d. 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</li> <li>e. Need to build pathways to work, not just for those with EHC Plans, but for all young people with SEND.</li> </ul>	<ul> <li>c. Training is needed in settings around strategies to manage behaviour</li> <li>d. SENCO's need training around Year 9 Reviews and the Local Offer</li> <li>e. Need to further explore the need to embed SALT 'communication environment' in FE's and ASC – potential for QE2 to offer some training</li> </ul>

E	Early Years	2. Mainstream	3. EHCNA Process	4. Health /	5. Social Care	6. Post 16	7. Training
				Therapies	Provision		
Pag	SEN funding in Early Years settings?	beyond - "s/he has had a good day" g. Communication	f. Examples of Key Workers saving information on their own spreadsheets and not on a central data base which then isn't transferred prior to leaving. Parents and professionals are requested to resend information.	<ul> <li>f. Outcomes of SALT re-tendering needs regular communication with parents.</li> <li>g. More work required with CAMHS around</li> </ul>	<ul> <li>f. Services are very limited for children who are high functioning or their siblings if they don't have a EHCP</li> <li>g. Siblings of children with SEND are</li> </ul>	f. The quality of SEND provision in colleges needs more scrutiny	
Page 100		<ul> <li>Passports should be carried by children to inform all teachers of their needs enabling staff to plan better and manage agency staff.</li> <li>h. Examples of</li> </ul>		supporting schools in developing strategies for supporting children who are self-harming, depressed or with challenging behaviours	often neglected – how can we improve this?	g. There are examples of young people who were SEN support in secondary school	
		exclusions of children from school trips is a concern – this	h. SALT is not available at SEN Support – this		being asked to leave colleges because they can't manage there		

Early Years	2. Mainstream	3. EHCNA Process	4. Health /	5. Social Care	6. Post 16	7. Training
			Therapies	Provision		
Page 101	needs further discussion with SENCO Forums in first instance.		<ul> <li>needs further unpicking.</li> <li>i. What are the transition protocols between HV and School Nurses?</li> <li>j. Communication between School Nurses and parents requires improvement.</li> </ul>		<ul> <li>without significant support.</li> <li>h. Transition is too late between Children and Adult Social Care</li> <li>i. Data and information sharing between Childrens Services and ASC needs significant improvement.</li> </ul>	
			k. Parents suggested training for Health			
			Staff such as GP /			

Early Years	2. Mainstream	3. EHCNA Process	4. Health /	5. Social Care	6. Post 16	7. Training
			Therapies	Provision		
			HV/ School Nurses on the Local Offer			
			I. Is it possible to			
			hold dental and			
			vision			
			assessments in			
			Special Schools?			
			Process of taking			
			children to			
Page			appointments is			
<del>) 102</del>			extremely			
к К			stressful			