

**SUTTON PARENTS FORUM
LOCAL AREA REVIEW
4 OCTOBER 2016**

In the second week of the Local Area Review, we are looking at **what it feels like to be a young person, parent/carer and family with Special Education Needs or Disabilities** and how effectively Sutton meet those needs and/or disabilities. John Hutton (JH) is getting statements from parents to say what it feels like for these families in Sutton. In terms of identification where families were at the centre of identification, this has worked very well.

CQC Ofsted will inspect the Sutton local areas and see how effective they are in identifying needs, meeting needs and improving outcomes, independent living and being as healthy as possible.

There is a strong feeling that support has gone from Sutton such as the key workers. If a need is identified between the ages of 0-5, the journey has been more straight forward for the family concerned. As the child gets older, education becomes more problematic. The professionals are not identifying SEN early enough, especially when the child shows no behavioural issues at school and all the behaviour comes out when they are at home.

The CQC Ofsted HMI have access to all the information they need, the right people and during the week of inspection the officials visit the schools and set up meetings with parents, families and the young people.

Q Do these people go to specialist and mainstream schools?

A They will choose specialist and mainstream schools to visit.

Q At the meeting last week the group of parents named three schools who they have identified as failing. Will inspectors look at revisiting these schools to see if any improvements have been made?

A There will be data studies showing attainments using a range of data sources that will help them decide where they want to go; they will also be looking at the health and social care relationship. The Thursday will be used to engage with parents and families. Ofsted will also run a webinar to communicate with parent/carers in the evening.

Q Are there any reports to see for the counties that have been inspected already?

A Yes. Seven out of eight letters are on the Ofsted website and HMI have produced a video. The eighth letter has not been published yet, however inspectors can see a theme emerging that local areas are not prepared for adulthood. Parents

are not properly involved and the quality of EHC plans were inadequate in some inspections.

Q Who chooses the schools?

A Ofsted choose schools they want to visit but JH encourages the Local Authority to establish purpose groups and give examples.

Q What is the aim of these reports?

A These inspections reassure families on the implementation of the current practice and provide the local area with a clear plan of where to improve. Better views go into their action plan and advice will be given on how to deliver these views.

Q What is the pressure on the Local Authority to implement these changes?

A The pressure is the public domain and parent power. When the letter is published, the Press and DfE will look at the letter and for good examples and areas for improvement within this. In the area that is not doing so well, the lead is taken from the action which is closely monitored.

Q Does Ofsted have any control over health, NHS and OT not being provided or given? I have been told that the school has to provide OT but does it come under health or education?

A The local area is doing a self-evaluation which should ensure clear information is published ie. whether it is education or health. The inspection teams are made up of a health inspector and a Local Authority inspector who both look at health. It also talks about joint commissioning.

Q How does it work if the child goes to an out of borough school?

A The Local Authority needs to know that the provision is meeting their needs and a member of the Local Authority should go the child's annual review.

How effectively does the local area assess and meet the needs of children and young people who have SEN and/or disabilities?

- Parent example of good practice; there is now an Inclusion Officer at Barrow Hedges Primary School who has implemented a range of interventions including providing support for tennis and providing 1:1 support so the child can access after schools clubs. Another parent noted that their child goes to NHS physio every second Tuesday and the morning TA goes to private

physio with the child every week. Parents felt this worked as the Inclusion Officer had a dedicated role in the school (not a class teacher).

- There is a good engagement with my child's school but this should be consistently good in all schools. Schools vary from great to poor and the schools' responses to parents are not consistent. There is a lack of engagement as far as medical and educational needs in schools with no joined up working.
- There is a resistance to start process of identification and parents are still not listened to, despite knowing their child best.
- IEPs are not being measured and followed with SMART targets.
- Diagnosis is parent led and is often blocked due to funding, which parents are very aware of. It is then a lottery of who you get referred to.
- Parent grapevine is still the best form of communication.
- EHC plan has not included medical needs of the child and it is not clear whether the health needs have to be met formally as an educational or health need. Reports have to be written well to ensure the local authority acknowledges them and incorporates them into the EHC plan.
- Self-assessment forms for social care such as short breaks are a bad idea. This is a poor way of assessing families and totally inadequate. Too much emphasis is made on filling forms out and the best support will go to the people who are most competent at filling in forms. Parents need someone outside the family to assess and there needs to be better involvement from professionals. EHCPs are of poor quality and, in some cases, not fit for purpose. They should work more closely with parents face to face, even it is in group sessions and also with the Parents Forum who are the parents voice.
- No-one knows who their key worker is from Social Services. In other boroughs, there is a key worker through the family information officer and the parent only found this out a year later.
- Free nappies are only given in the form of nappies and not pull ups, but nappies are not appropriate for all children as some can only wear pull ups.
- As far as appointments are concerned, there is a battle to get seen by professionals due to staff changes etc.
- The parent has to be proactive to advocate for your child and finding out what is needed in an EHC plan is very difficult. If you are not vocal, you end up with a low quality EHC plan so mentorship is very important.

- One child had an EHC plan from pre-school which still took nine months to sort out and the child needed 1:1 support. The child was kept back at pre-school due to lack of support. The parents were written to in the school holidays before starting in September at pre-school. The NHS physio said that full time support was needed because of mobility but the Local Authority only gave six hours. School paid for full time support and then the Local Authority gave ten hours.
- A Statement was written in pre-school. The child is now in Year 4 and the statement does not reflect their current needs. School requested an Annual Review so the Statement could be transferred to an EHC plan as this was not relevant. The Local Authority refused.
- The Case Officer had never been to an Annual Review for a young person who is now 18. He is now at Carshalton College and the Statement ceased at the end of school. This went to Panel for an EHC plan and the young person is struggling at college. LA will not fund support and there is no clear information.
- EHC plan timescales are not being met and EHC plan reviews are not on time.
- The EHC plan was not timely for my child. We were invited at the last minute but there was no social care report or involvement.
- A Statement was done two years' ago and there was no Annual Review as the child was in hospital and the conversion to an EHC plan has now been delayed until March 2017 which is far too late.
- I was sent the draft EHC plan the night before the meeting and did not have time to read this thoroughly.
- OT is only commissioned in health and only under duress with fight for parents, causing more stress. OT should also be paid for if it is an educational need. There are too many arguments about specifics, ie sensory processing.
- OT is stuck between the Marsden and SEN team. NHS staff say they do not have sensory qualified paediatric OTs which needs early intervention. Refusal to provide specialist trained SALTs and OTs has been an ongoing issue for at least 10 years.
- OTs will only visit between 9-5 and do not do home visits outside of these times, therefore not seeing the problems at home. An official complaint was made to find out about St Thomas.

- There is no set process for transitions and a parent had to fight to get information feeling that it was up to her to find out about transitions herself.
- Once a diagnosis is received, you are abandoned and not supported. Emergency cover is needed together with mentorship as you are left feeling overwhelmed and under supported.
- There is no way of monitoring how the child is progressing to identify whether their needs are being met. The same question is asked time and time again.
- My son was 16 having attended mainstream school and doing GCSEs before being identified as needing specialist education. Unless you are disruptive at school, nothing is done. In the end my local MP helped get him the education he needed in a specialist school.
- There needs to be a one-stop-shop on what is available for SEN children as no-one is ever told.
- Some parents do not always want to speak on Webinars as there may not want to be identified. Will these webinars be used in the public domain?
- In the SEN Code of Practice on which EHC plans are based, this does not look at best practice for Downs Syndrome children as they learn in a different way and is guidance rather than mandatory. If you need extra help, there is an All Party Parliamentary Group which gives guidelines but because it is not mandatory, it is not considered. The Code of Practice sign posts people for extra help but only mentions four groups and there is no sign posting for Downs Syndrome children.
- Appropriate staff need to be in place and properly trained to meet the needs of children with SEN.
- SENCOs have too many responsibilities and roles and are therefore too busy to deal with SEN issues.
- Westbourne School has no time for special needs children and was academic and sporty.
- The unit at Amy Johnson is very good.
- The Speech and Language unit is good at Muschamp.
- St Mary's, Carshalton know that there are behavioural issues but not helped if they have an SEN plan as there are no resources to put this in place.

- My daughter did not quite fit into Carew but does not fit into mainstream either due to the remit of the school being changed.
- More schools are needed where special is not the answer but mainstream is not for them.
- Parents have often been blamed for bad parenting skills rather than trying to get a diagnosis for the child.
- There is a lack of links between schools and GPs.
- Private reports are not always considered as medical evidence and often ignored. One parent has received help from the Downs Syndrome charity which provide and pay for SALT and OT from specialist therapists. These should be considered as they are specialists.
- OT recommended in the child's statement or EHC plan is not usually enough. My child has only been able to attend mainstream school due to receiving sufficient OT. I was told that the OT did not have time to see my child because there were other children with more needs. The communication between the Local Authority and the OT is poor and they Local Authority and the CCT blame each other.
- My young person's OT did not sort out problem for me and had to find another one due to lack of progress.
- The Local Offer could be renamed as the name itself is not obvious in what information is provided.
- The Local Offer does not work so well on the phone as the Local Authority assume that people know how to use the website to find information. Every opportunity should be used to promote this. Downs Syndrome Day was under 'latest news' and not 'events' and therefore was not easy to find.
- Paediatricians are only trained to work with young people up to the age of 18 so what happens once they exceed that age? No guidance of where to go from there.
- The Local Authority are better at following recommendations from specialist schools and only then will they finally listen.
- The Local Authority do not listen to recommendations from mainstream schools when they identify needs and statutory assessment is usually turned down. Delaying tactics are used to prevent extra funding being made available for the child yet early intervention is best practice.

- The Local Authority push to the last minute so that they can minimise what they pay. Consequently, emergency funding/support is needed which is counter-productive. The Local Authority work on a funds led policy rather than needs led for SEN children.
- There is a lack of respect for parents pushing them to breaking point and the SEN Team show a distinct lack of empathy and some of them are actually very rude. There is SILO working where departments do not share information.
- Local Authority staff are often abrupt with parents and no-one from the SEN team attends annual reviews unless there is an issue.
- There is a lack of ownership between the Local Authority and health with parents having a lack of trust for the Local Authority. They need to recognise that you are overwhelmed and under supported with many parents suffering from depression and stress.
- Many young people have to go to schools out of borough to have their needs met due to lack of provision locally. More 16 year olds have ABA which cannot be met in borough. There is also a lack of support from the Local Authority if you attend an independent school out of borough.
- There is late agreement for funding for post 18s and this only agreed three days before the end of term.
- The system is adversarial causing parents to be very cynical in the end.
- The ASD team were very good. My daughter had a late diagnosis and the ASD team went to school and she stood out, so was identified straight away. A member of the ASD team, Michelle Fisher, went to the meetings at school and at CAMHS with the parent. She was very creative. However, it is questionable how much information is being passed from the ASD team to schools.
- There is a high turnover of staff in the OT department and the good ones always leave. One member of staff left because she was fire-fighting and was prevented from doing other work. Staff are frustrated and are not allowed to do more to help.
- Local Authorities work to their own timetables despite parents meeting theirs and meetings are often cancelled at the last minute.
- There is a tendency for the Local Authority to send emails late on Fridays so that there is no recourse and worry is caused over the weekend.

- Second opinions are not readily available and parents are forced to accept the Local Authority or their professional's opinion. System for complaint procedure is not transparent.
- Parents are not listened to so there is a problem with progressing through the maze even though they get there eventually. They felt that obstacles were put in the way so that grant applications are turned down. Parents feel emotionally drained and have reached the end of their tether.
- You should be able to champion people who do their job well and get them to share best practice. More upward spirals are needed for parents
- Once you get the help from professionals it changes your life. There should be an Awards Ceremony for good professionals.
- There is a feeling that you have to battle with schools to get listened to and have your child's needs put in place.
- There is a 'pass the buck' attitude ie different therapists tend to delay producing reports and providing feedback, no liaison between departments.
- One parent was not given the identity of the cab driver taking her child to school until the morning when he turned up at the door.
- EHC plans are of poor quality and not fit for purpose in some cases.
- The Local Authority need to work more closely with parents face to face even if it is in group sessions and also with the forum.
- A lot of money has been put into CAMHS but people are still not happy with them.
- Parents have very different experiences from one CAMHS to another.

JH fed back from discussions that school leads do not provide the best services. Schools do their best to meet needs of young people considering their resources. When outcomes are mapped from an early age, it is easier to manage. More co-ordination is needed over assessments.

Short Breaks

There are people who do not know what this means. One lady had a CAF form rejected because she did not use enough words to specify her child's needs. By the time you receive any type of short break, you are at breaking point. There is no joined up working.

One parent received direct payments for her ASD daughter but nothing for her daughter with cerebral palsy. Eventually, this was rectified after lengthy discussions.

One parent has had to pay private for respite so she can spend time with her other child.

The other question raised was why parents could not go to Panel meetings.