

**PARENTS FORUM  
LOCAL AREA REVIEW  
20 SEPTEMBER 2016**

John Hutton (JH) is employed by the Local Authority as a consultant to help with the local area review which is the self-evaluation of services and performance in Sutton including education, health and social care.

In terms of SEN and disability self-evaluation, JH and the Local Authority are writing a Statement for the front of self-evaluation report, reflecting what it feels like to be a family/parent of a child or young person with a disability in Sutton.

In terms of background, this is part of the Children and Families Act 2014 and the Local Authority are responsible for ensuring the Act is implemented appropriately. Sutton and other areas will be inspected by HMI (Her Majesty's Inspector), Ofsted and the Care Quality Commission who will complete this inspection within the next five years.

Part of the inspection is to work quite closely with parents and children and young people (CYP). During the week the inspection takes place, two days are spent interviewing Disability Children's Services and Councillors. On the Wednesday, a visit is made to Early Years settings and special schools. On Thursday a variety of ways are used to seek the views of parents and a Webinar will be run so that parents can take part in the form of an online conference.

The purpose of these parent forum local area review meetings is to gather families' view on the key areas that will be inspected.

Every borough will be inspected but will only be given a week's notice before this takes place. The process of self-evaluation is ongoing. We want to identify how families feel how the local area is implementing SEN reforms and influence an action plan on what improvements are needed.

Eight inspections were undertaken in the summer term and further inspections have now begun again. Of the eight inspections most of the letters have now been published.

Three areas of inspection are:

- How effective is early identification of needs?
- How effective do they meet their needs?
- How effective are outcomes for children and young people with additional needs and/or disabilities?

There is a You Tube link by HMI's Lead Inspector, Mary Rayner which is on the Local Offer website.

[Local areas - a new inspection framework being introduced - YouTube](#)

Q Once the Ofsted report has gone to the Local Authority will it be checked to see if these plans are implemented and put in place?

A CQC Ofsted will send and publish a feedback letter with their findings and recommendations. Sutton are showing their commitment to this process by employing John to lead the self-evaluation process as he is independent.

The self-evaluation team has produced a one-page summary produced from access to data. This is a statement of how it feels to be a parent in Sutton and how they think they are doing.

Q Is the self-evaluation a voluntary assessment?

A The self-evaluation is good practice and the inspectors get an idea on how the Local Authority is performing. The first part of the self-evaluation project focussed on 0-5 with primary schools and Early Years. Health people are not allowed to self-evaluate. It is also an opportunity to see how social care works. JH tries to triangulate all three departments to see how effective Sutton is in identifying SEN.

Q How are parents going to be identified to give feedback when Ofsted arrives?

A The notes from these discussions will be used for this. JH and Ofsted will communicate through parent groups including the Sutton Parents Forum and they will run a Webinar. This usually takes place on a Thursday of the inspection week between 5 and 7pm.

Q Is this meeting different from the July meeting regarding the Carer's Strategy?

A The Parents Forum fed back the views from that meeting into the National Carer's Consultation. These are on our website and were sent out by RB to the SEN Reform Group.

Q Why do the Local Authority block the identification of needs and is there a difference in identifying different age groups?

A A discussion ensued where parents felt the Local Authority had refused to acknowledge their child's difficulties and, therefore, identification need had been unnecessarily delayed. Parents felt it was harder to get support in identifying needs once children had entered mainstream school and this became harder as they got older.

### What does it feel like to be in a family and a parent of a young person with SEN?

- Three schools were highlighted as being particularly unhelpful:
  - Green Wrythe Primary School
  - Westbourne Primary School
  - Cheam Common Junior School
  
- My daughter did not have a two-year health check by a Health Visitor as I was told that this was not common practice now, therefore early identification and intervention did not happen.
  
- I identified her at 2 but she did not receive an official diagnosis until she was 9. She then was admitted to Tier 4 hospital for nine months. Emma Aldridge completed the CAF form and the hospital advised that the parent needed urgent support in the form of a residential school. There was no CAF or EHC plan. She was then discharged from the hospital which was outside Sutton but there was no joined up working and Sutton had no knowledge of what was going on and support services were not put in place when she left hospital.
  
- My daughter was at a private school at which there needs to be a more regulated approach in identifying Special Educational Needs.
  
- There is no collaboration between Sutton Local Authority and parents for monitoring of private schools. These schools need training and they lack understanding of the EHC process.
  
- Telephone calls and emails to the Local Authority (The Grove) are ignored and not answered making communication very poor. There was a total lack of empathy from the Local Authority in terms of communication with the parent.
  
- A family support worker is needed at the start of the process when trying to get professionals to listen to parents' concerns at SEN not being acknowledged.
  
- There has been positive feedback from Nurseries, Woodcote Nursery in particular.
  
- Woodlands Day Nursery at St Helier Hospital was excellent in terms of support and making referrals for children with additional needs as well as the EHC process. There are two SENCO workers who were very proactive and supportive with referrals and completion of forms. The children had their Special Education Needs identified early and they were supported with evidence that was required for the EHC plan.

- There is a loophole in the Occupational Therapy (OT) system as parents are told that OT assessments stop at 6 and the waiting list is endless, so how can a child get OT who desperately needs it?
- Resources for Educational Psychologists are too low so children take longer to be assessed.
- St Cecilia's Pre-school were very good in identifying my child's needs and there was a very good referral process for Speech and Language (SALT) and OT.
- Another had had a very different experience at St Cecilia's and this raised the question of why families would be treated differently.
- The system for Statutory Assessment needs improving and more joined up working. There is a lack of Educational Psychologists (EP) and often Statutory Assessment will not take place until an EP report has been submitted. When a private EP report has been written, this has not been taken as sufficient evidence and delaying tactics are used to delay the process.
- Nothing has changed at all for people 16 years upwards so the SEN reforms have not improved services for young people of 16 years and upwards.
- Parents who have learning difficulties or issues themselves are not able enough to advocate for their child due to being undiagnosed themselves and not receiving enough support to get the help they need.
- Often children in school seem fine and not on their radar as the behaviour usually comes out at home. The system fails at an early age and needs are not being recognised. Teachers need more training.
- It is very sad that schools see parents as "pushy" as they do not feel heard when expressing their concerns that their children are not having their needs met.
- There is room for improvement for recognising parents as carers regarding support which is needed and this is still not happening.
- There is a lack of key workers around transition times. There is also a lack of communication around social care. A parent tried to contact the Specialist Nurse and had not been told that she had left the Children with Disabilities Team.
- Not enough joined up working is happening with health and social care and schools are not referred on to social care and health.

- The parent of a child who was incontinent was not told about free nappy services and only found out today through another parent.
- A child who was wetting themselves during the school day was not allowed go to the toilet during lessons. There was no change of clothing, making the child very uncomfortable for the rest of the day.
- No joined up working between schools and CAMHS and the GP told a parent that there was no point in writing to CAMHS as the waiting list was too long and their child would not get seen.
- It is often necessary to go to the most senior person to escalate anything being done as you have usually reached crisis point by then.
- There is always a need to reduce budgets by the Local Authority yet people get to crisis point, costing the Local Authority more money in the long term. This should not be allowed to happen.
- More schools are needed locally which cater for children between mainstream and specialist and the criteria keeps changing for maintained schools eg Carew Academy.
- My daughter is in a mainstream school and was not offered any specialist courses in place of GCSEs. She was basically offered GCSEs which she would fail in. However, the Head Teacher at Overton changed the timetable so that she could do specialist options ie. How to travel on a bus and how to handle money.
- A lot of people do not know what the Local Offer or short breaks were. The Local Offer is difficult to read. Although it is well structured, it does not reflect how Sutton works.
- One parent had a Stroke who has a daughter with SEN and another child with a severe allergy. When the parent asked for respite care, she only had an offer of removing the children and having them looked after for her but nothing for herself.
- A parent was asked to complete a CAF Self-Assessment Form for short breaks. She expressed that she could not do this and generally forms always come at the start of the summer holidays when it is impossible to get these things done.
- Dyslexia children are often off the radar in being identified for help and support and there is no health or social provision given. Children with dyslexia are not seen to reach their potential through lack of help.

- The Local Authority are very selective in what is included in an EHC plan and medical advice often ignored.
- Teachers and SENCOs need more training on SEN. SENCOs' knowledge of the process for EHC plans is poor so more training needed there as well.
- One EHC plan referred to a child by the wrong name and also gave no strengths for the child.
- Another EHC plan has had seven drafts. The spelling and grammar was very poor and it was very selective on what was included. No medical evidence was included at all in the EHC plan. It was not factual or tangible. There is a distinct lack of ownership.
- Another EHC plan was sent out late and the parent received this the day before the meeting so did not have sufficient time to look through it.
- Sutton Parents Forum have been fantastic and their Independent Support Service has been invaluable working very well.
- Parents do not seem to know what makes a good EHC plan and there is a distinct lack of sign posting.
- Sutton has a different approach to the EHC plan and decided to do the plan before the evaluation.
- Parent Partnership told my daughter's teacher that she did not need an EHC plan when it was obvious that she did.
- One parent was turned down for an EHC plans there was no paediatric assessment, making it too administrative. Her daughter ended up needing 7 day residential care because of this.
- The Local Authority do not know how to do EHC plans for colleges and have no experience of this.
- Educational Psychologists' reports are needed, but Sutton are confused on whether they would allow and EP report and people are unsure on what constitutes a good EP report.
- Money is spent on the wrong places. Panels are seen as blocking tools and do not read reports.
- Appointments with professionals are always during the school day and there needs to be flexible working with an extension to their day so that children can be seen out of school hours.

- If a child has a genetic condition they often get access to services quicker than children with behavioural issues.
- One parent read a report referring to a medical condition that her child had and had never been told about this previously.
- If there is support from a GP or Social Services, you are less likely to get a diagnosis for your child.
- There is a lack of support for parents regarding paperwork and more help is needed ie CAF forms.
- One parent had to video her child having meltdowns at home in order to feel listened to and to get an EHC plan for her. She also captured on video measures that had to be taken at home to keep her daughter safe.
- No 2 year check was done for my daughter and when a 2 Barnardo's workers were assigned to work with her, they didn't stay as they couldn't cope.
- There needs to be an increase in parental support in CAMHS as this is lacking.
- Triage is not functioning and parents need to be listed to more.
- There is an underlying block and funding need is the problem. The borough is not trained. Sutton uses the school but block children moving towards diagnosis and a triage system is used by schools.
- One parent used to be a Governor at a school. The Deputy Head and SENCO were very good at identifying all children with SEN at an early age. Parents wanted their children to go to this school because of its reputation in this regard.
- Departments do not link together because of budgets
- CWP social worker was very good.

### Input from parents via Email

Can you please explain why there is one meeting during work time?

You are 'hoping as many families as possible will contribute' however every meeting invite is always during the day, who is not helpful to working parents. Then there are the coffee mornings, what wrong with a coffee evening?

I would also like to know how much information will be filtered before given to OFSTED as effective early identification of my son was extremely poor and it is pointless giving that experience if it will not be submitted. Sutton are obviously wanting a good OFSTED report. Should parents be invited to send in direct to OFSTED for an accurate report?

I look forward to your response.

Phoned to discuss and SPF will run an evening session.

I've received the letter about the above. I cannot attend the meeting but wanted to put a point across by email.

I live in Worcester Park, in the area that falls under the Borough of Sutton. My son has an ASD diagnosis. I think the Ofsted review should look at the areas where ASD bases schools are located. Most seem to be in Wallington / Carshalton / Sutton. There is very little provision in the area in which we live.

Dear Jane,

I am happy to contribute our experience via email.

My nine-year-old daughter has a diagnosis of Asperger's syndrome and ADHD as well as some significant sensory issues that were noticed and documented in infancy. When she started school we brought our concerns to the school in an attempt to get support as well as a proper diagnosis. We have had a horrific time in Sutton. Both the school as well as the Sutton ASD service dismissed our concerns as "bad parenting." We have had to fight every step of the way to get anyone to pay attention to my daughter's needs. The school and the borough have not been supportive of our family or our child. The only reason my daughter has both of her conditions diagnosed now is due to my own determination in seeking out help repeatedly after our concerns were ignored time and again. If I had not been a teacher with access to support at work, I do not know that I would have been able to continue to fight.

Based on our experience, my husband and I believe that the schools do a very poor job in identifying problems in girls. While there are many boys receiving services in the borough, we have been told repeatedly that our daughter does not have the same level of need because she does not behave the way the boys at her school do. We feel that most educators are not experienced in dealing with girls with special needs, particularly ASD and ADHD, and that there is a good chance that there are other girls like my daughter who have not been identified because girls are not on the radar or seen as needy as the boys.

If Ofsted wants to do a proper investigation, they need to look into how girls are treated in Sutton.

Dear OFSTED Team,

I am a Sutton resident and parent of a fifteen year old son on the autistic spectrum. I also work with people with special needs, but not in Sutton.

My son attended local church pre-school and primary school in Cheam and now attends a Church school with an autism specialism in a neighbouring borough. Fortunately, staff were aware that he presented with language and communication difficulties and he was able to get an educational statement with 12 hours support by the start of the reception class.

All educational establishments he has attended have done their best to meet his needs. The only times when there have been great challenges have been when there has been a change of need for an increased need of provision when my son required more support which needed an increased budget to enable this. Even when there was clear evidence from school and home also confirmed by tribunal judge, with lack of progress or regression in areas where further support was required it took over a year each time to gain the funding required for the additional support. When the support was increased there was clear evidence of progress. I know that the severe constraints on local authority budgets have a huge impact on the funding available which impacts on the process, with only a limited pot of money that everybody has to fight for to get their child's needs met. However, there is great stress that affects the child family and school when financial aspects influence support access.

The services within Sutton however have been very good in their provision. The short breaks service has made a huge difference to our son and the whole family. He has had breaks with a KIDS short breaks worker who has taught him many skills whilst taking part in a range of activities around his interests. Val will visit museums, play football in the park, talk about the stars and planets among many other activities. He is able to talk to her about his worries and this helps him to process situations. The SMILE activities are excellent and are his only real social life with peers out of school as despite many attempts friendships have not formed long term with those whose interests and developmental stages are further ahead than him. With a buddy supporting him he gets to take part in activities a teenager would in a supportive learning framework which is at his interest level and he has opportunities to input. The best thing is that there will be a pilot to have an 18-25 year group soon. This has been a worry for lack of provision for the next stage for many parents. My daughter also loves volunteering with SMILE and it has benefitted her experiences too for medical school. She will be a team leader when she has breaks from Cambridge. Excellent service, long may it continue to benefit families.

The Sutton Parents Forum has been very good in terms of the support offered to parents and families. This includes support with transfer to the new EHCP, courses, parent meetings with borough staff on specific topics as well as sports and social activity programmes for young people with special needs during the holidays.

Sadly missed is Contact a Family based in Sutton as funding did not continue. The support for families, input, courses, workshops, coffee mornings with speakers and young people's activities were a great help for families at all stages pre or post diagnosis and a mine of information on all sorts of topics and local information, including their excellent guide for activities in the local area.

The Educational Psychology Service, particularly Michelle Clubb a specialist in autism was excellent on her assessments as well as family input. She was spot on with everything she said at point of diagnosis in primary school and recent assessment for EHCP plan. She is extremely efficient and professional.

The NAS Sutton has recently had a group of new leaders and there is weekly information by email and the recent speaker a dad who has written a book about a young person with autism also drew in the men who asked the majority of the questions.

The ASD service has been very good, when our son was in primary school input on the sensory issues he was having and sessions at Tweeddale sensory room. What I learned transferred into activities in the home environment.

An ASD course run by the ASD team was excellent and finally got my husband attendance this year. He is more observant and accepting if needs as a result.

The CAMHS support linked to our long term family GP in a neighbouring borough was excellent. However, I'm told that Sutton would have been different and probably only 2 or 3 appointments. It made a huge difference and I understand the Sutton service is very overstretched with staffing, budgets and waiting times from a previous parent meeting.

The SCILL Centre has also been a good source of information. My son uses the cafe and gym there in the summer holidays and some SMILE short breaks. I hope our son may get some computer input there in future as the school curriculum was too challenging in terms of specific jargon and language processing, although he is a very fast visual learner with computers.

The SCILL cafe is used by members of the public and run by adults who are supported in their skills. It is a valuable place for learning and somewhere families can come with young children with additional needs with toys and nobody minding if they play or make noise. Several parents meet there. I believe it is a service under threat of closure for this cafe.

I would appreciate more input and support on post 16 options as there is a very long list of options on a sheet and a more personal point of view would be welcome from others on services and comparisons of different provision. Perhaps a parent workshop or specific supporter for this process would be useful.

The transport system is working well at present for our son.

From a parent's point of view Sutton is a good place to be on a number of levels if you have a person with special need, but budget constraints are having an impact on services.

Dear Sutton Parent Support Service

I received a letter from yourselves about the review of some of Sutton services and Ofsted.

I was unable to come due to work comments sadly these meeting never consider this parents who work.

Please can you therefore pass this information onto the Ofsted.

Scill payroll are the same only open 10 to 4pm which annoys me I work 9am to 5pm.

However, I will list the issues of concern on a variety of services for young people like my daughter with complex needs.

1) The Inclusion centre waste of money running it as they do I have had various confirmations meeting and correspondence to managers' health professional including councillors it got me no where

It's too expensive to hire & really under used in all aspects.

I think Sutton are running it down to sell it off.

When organisations like Mencap and organisation who support young people with additional needs could use it!

There are very limited services for young people with complex needs so hand it over to experienced organisations that support young people with needs who will make good use of it!

2) The Mencap building is too small and there is not enough provision for wheelchair users very limited spaces available.

3) We as parent Carers have to do all the research to find out what services there are for young people with complex needs after 19 years' lack of easily available no information no sign posting.

4) Orchard Hill not experienced with MDVI when my daughter started 4 years ago they were only just exposed to providing for such learners.

The management is poor they are not constant they are awful at communication they lack confidence and are not sensitive to parent carers.

This last year has been especially poor changes in staff people who don't know my daughter inappropriate comments.

Not sending medication home. Insisting that I collect my daughter even though I'm working because her sling is wet, when they could have washed it.

No using standing frame because of bad communication for 3 months.

Loosing things and she has had 5 one to ones since January to July 5 this year no consistency (they told me three but when I challenged this is was more). Which makes things worse as more lack of communication between them because they are not constant. At school my daughter had a consistent one to one its required for her needs but Orchard Hill insist they don't work like that as they need to expose them to real life. Real life for my daughter in all other environments is consistent one to one never had any problems anywhere in providing this else but at Orchard Hill.

staff.

4) Orchard Hill have not contacted me during this year to ensure I'm getting help or support from them for transition they have forgotten my daughter totally and that she leaves in 8 weeks.

5) Sutton Education refused my daughter an EHC plan & I could have challenged this at tribunal but because I've lost faith in the college I won't do this.

However, because Sutton had not addressed the transition issues for my daughter they had no transition plan. Hence they are giving her a place there for 2 months this term, how ridiculous is that she goes in Sept and leaves in Nov how unsettling is this?

The code of practice says until the day before her 26th birthday if her 25th birthday falls in the educational year she is in.

I know this because I am an Educational Advocate.

My daughter is in the 3rd week of this term and she only has about 8 weeks left & no one from college have called to ensure we have something for her or met me to discuss this we are left to sink or swim.

They offered to meet with me over the other concerns I had but not transition.

In terms of the meeting tomorrow the thing we have major issues with is still identifying the need for OT and being able to access adequate OT. Many children with Down's syndrome attend mainstream school, which we are encouraged to do as children with DS are very good at modelling behaviours and learning from their peers, as I'm sure you know. I'm sure you also know that getting access to OT's can be difficult and many parents in the Borough attend charity support groups where they are able to access OT from specialist therapists before they attend school. These therapists ALL know the child better than their NHS therapist as they see the child every week, but when a report is submitted for the EHCP this report is ignored in favour of a less specialised NHS therapist who may have only seen the child a handful of times!

I would say that not acknowledging private reports from specialist Down's syndrome therapists makes it a bit difficult to identify the need for OT for our children! Once a need is identified it is then difficult to access OT as it is not funded by education and our children will only get OT in their mainstream schools if there is a health need. Our children have very low muscle tone and therefore OT is very important in terms of fine motor skills and a multitude of other activities which would come under an educational need. This obviously is different if the child attends a specialist school where they would have better access to OT. You can, I'm sure understand our frustration!

Unfortunately, I cannot attend this morning. What I would say is for those children who don't have what I would call an "obvious diagnosis" you slip through the net and are unaware of any services or support available to you. We were told constantly that our son was a "late developer" with ha speech and so didn't access portage or anything else. This was not the case and without "special need" friends who I have since made and the wonderful ladies of parent partnership I wouldn't be in the place I am today.

My experience of early intervention with ASD is vastly different to that of a child with Cerebral Palsy (CP) - I have an 8 year old daughter with ASD and a 4 year old daughter with CP.

Most children with Autism are diagnosed about 3 years of age (if not much later for girls) but Portage ends at age 3 and there is a gap between the end of Portage support and when most children start school at age 4. In our case we were on a waiting list for Portage and then received 3 months of Portage until my oldest daughter turned 3. Then there was a 7 month gap when we received very little support as we were waiting for our, now 8 year old, daughter to start preschool.

Portage did keep in touch and helped get us a place at Dragonflies but not in an official capacity because of their age limitations their support was limited.

The only (ir)regular support we received was speech therapy which was every 3 months and a consultant paediatrician who saw us every six months. We paid for private speech therapy in the interim. The NHS speech therapist only saw us every three months and then complained when we used private speech therapist as the methods might confuse our daughter - but they were only seeing her every 3 months and the private speech therapist agreed to follow the same program.

After waiting 6 months to see a NHS paediatrician the registrar told us that we would have to wait 6 months for us to see the consultant.

By the time we got to see our consultant she was surprised that we had a place in Dragonflies Assessment Unit because it was so sought after and she hadn't referred us.

The paediatrician's support for Autism for early diagnosis was extremely lacking. All they did was diagnose our daughter and refer us to other experts such as a gastroenterology and a geneticist which was my request (not theirs) as we sought to find answers. Not long after she turned 6 we were signed off by the paediatrician and told that there was nothing they could do all her needs had to be met by the education system which they weren't as a subsequent court case at the SEN tribunal proved. We proved that her primary school wasn't meeting her needs and she needed one on one ABA support which she is now getting at school out of borough.

But back to early intervention - it is a major flaw in the UK health system that Autism isn't considered a medical need but a developmental need. In the US therapies are covered under the private health system. At this time, we had private BUPA and were told our daughter wasn't covered as it was a developmental issue. So we were dependent on the NHS who wasn't equipped to help us.

So basically there was no easily accessible early intervention for my child - despite us wanting to get it we just didn't know where to look. I asked several professionals about Applied Behaviour Analysis (ABA) but was put off as they said it was very expensive and we had to do 40 hours a week. The 40 hours a week input is incorrect and it is disappointing there was no sign posting to places where we could get it. Of course the ideal would be that it was available on the NHS but this is an entirely different debate.

We were told that we had early intervention because we had a place at Dragonflies ASD assessment unit. At Dragonflies we received no practical training apart from guest speakers and slide shows - there was no hands on input and we were never invited to an OT or SALT session once our child entered Dragonflies and then her primary school. We were told we couldn't come in and observe as we would upset other children.

What is lacking entirely in this scenario is parent empowerment and teaching children properly with evidence-based methods. I have never felt so supported as I did when I started ABA when my child became the focus of the treatment.

It was through a home-based programme where I was taught how to work with my child that I started to learn key messages about reinforcement and motivation and how to address challenging behaviour. Why aren't these practical ABA methods introduced to parents and why is the educational establishment misinformed about ABA and its benefits. I asked several teachers at her primary school about ABA and they either had antiquated views about its use, were unaware that it incorporated natural environment teaching and wasn't just table work, or were completely unaware about it (which is shocking for a so called Autism professional).

It was through me doing daily teaching after school with the supervision of a board certified assistant behaviour analyst (BCaBA) that my daughter started to speak, started to sit and listen and follow instructions. She went from struggling with a 3 piece puzzle to completing a 20 piece puzzle in a matter of minutes. It was through me sitting on the floor with my oldest daughter every day that I realised the extent of her coordination issues and through me pushing for more 1 on 1 OT (it had been stopped at her school and a sensory diet put in because my daughter's attention and ability to follow the programme was so poor). What wasn't being addressed was her motivation and attention issues - she had already proven she would sit and concentrate when motivated (reading a favourite book or songs). I would argue that my daughter like many girls with ASD was looked over as she was passive and not creating a fuss. Her diagnosis was severe enough it couldn't be missed but her ability to learn was also looked over because the staffing levels were not adequate - she needed one on one and the staff attention at her primary school was either directed to the more challenging and aggressive children at the school or they simply didn't have the proper training to help her.

By me pushing for her to see physio because of the lack of any one on one OT My oldest daughter she was diagnosed with hypermobility in her upper limbs, something that her Dragonflies and her primary school, OT who had been seeing her since she was 3 failed to diagnose.

I probably wouldn't be so critical if it was all I had known. But when my daughter was 4 her 10 week old sister died after a cardiac arrest. She was revived after 20 minutes without oxygen. Her prognosis at the time was worse than her older sister but she has gone on to improve vastly.

My youngest daughter was diagnosed with Cerebral Palsy - correo athetosis or involuntary methods. The treatment and follow-up from the community health team for My youngest daughter was incredibly impressive we had a dietitian, health visitor,

physiotherapist, occupational therapist and portage worker visit us regularly in our home. We were provided with equipment and practical advice from 3 months of age and received Portage input from 3 months - vastly different to 3 years.

My four year old daughter is now in a mainstream school walking and talking independently, building friendships and is cognitively at the same level as her mainstream peers albeit with some SEN needs in relation to physiotherapy, OT and SALT.

While the NHS physiotherapy input has been extremely valuable I would still argue it was inadequate and only through being fortunate enough to afford private Bobath physiotherapy that my daughter has progressed so far. It was intense private Bobath that enabled My youngest daughter to sit up, and to start to stand and make steps and now walk alone. Her NHS physio input which was initially intense was dwindled to once a month and only through attending private physiotherapy and conductive education for children through the charity Small Steps in Roehampton that my youngest daughter has made the gains she has.

My youngest daughter's OT input has been lacking, and not adequate especially as she only receives 12 sessions a year and it will become a major need for her as she starts to write.

I realise they are two separate diagnoses with completely different needs and that their treatment will vary but what I couldn't believe was how much extra input my youngest received compared to my oldest daughter. I attended every single physio and OT appointment with my youngest daughter which made me realise how short sighted it was of the education system to not allow me to do this with my oldest daughter. By going with my youngest daughter I was an additional therapist who could work with her at home.

I would argue that the support for ASD needs to be much much better. The medical profession needs to work on an earlier diagnosis and measures need to be put in place to ensure ASD children are getting much earlier intervention. I would also argue that many children who can't afford private physiotherapy are missing out making major gains at a young age. By investing in additional input at an early age money can be saved in the long term.