

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

John Hutton (JH) explained that this was the third Local Area Review meeting focussing on **'how effective are outcomes for children and young people with additional needs and/or disabilities'** and he has received help from local parents and local authorities to self-evaluate on how SEND reforms are being implemented. JH has talked about identification of needs for SEND children and about how the local area is meeting these needs.

All local areas will be inspected by Ofsted to look at these three areas of need and how outcomes can be met for young people with SEND and other disabilities. JH needs to know what it feels like to be a parent of a young person with SEND and how outcomes can be improved in education, health and social care.

At this meeting, JH is looking in particular at moving to adulthood, being healthy, independent living and participation and how the local area is supporting us with these outcomes.

A parent said that her daughter is 18, but there is no outcome yet towards independent living as she has not reached that stage in her life.

Various discussions took place amongst each table and the following points were raised.

- My son is 20 who has an ongoing medical condition and is at a specialist school out of borough. He can stay there until he is 25, however, each year the Local Authority say that they cannot guarantee his place there due to additional funding. An annual review takes place each year and the place is only secured at the last minute, causing a lot of stress to the family.
- No-one takes ownership of the needs and outcomes for young people between the ages of 18-25.
- My daughter had a review of her EHC plan for going to college and commented on whether there was any point to this as the last one had been ignored and there is no guarantee that the college would implement this. The college was inspected by Ofsted, but parents were not informed that this was taking place and did not have the opportunity to comment on the provision. There is no mechanism for the Local Authority to monitor the college.
- The Sutton website is not generally very good, particularly regarding independent living as it is very much geared towards older people. This needs to be co-developed from the start and seems to be a box ticking exercise.

- There is no recognition of the young person's functional age as opposed to their actual age and this should be based on need rather than age.
- The process is too disjointed and there is no support for the parent from the Local Authority, therefore they are left very much to do things on their own.
- One parent was let down badly by the SEN team as her daughter's needs were not being met.
- There should be a key worker assigned to each child and parent/carer from birth to adulthood, including transition, to help parents through the EHC process. There is nothing to pull education, social care and health together and a more holistic approach is needed.
- The Local Authority rely on existing contracts with companies who they have used for years and are reluctant to research into other companies who could provide a better service.
- Parents who do not come to SPF meetings often do not know the process for an EHC plan so are more vulnerable and less able to advocate for their child in getting what they really need.
- A lot of mental health needs are not addressed and this needs to be monitored.
- Sutton CAMHS have generally provided a poor service with a few exceptions. A survey is needed to find out people's actual experiences and where their weaknesses are. They also need to listen to parents.
- Sutton is not listening or implementing improvements based on previous consultations.
- There needs to be more collaborating and co-designing with service users who can see where holes are and where budgets are slipping.
- Sutton Local Authority have good systems set up to put things in place, but so often nothing happens. Money is invested in the wrong places.
- There is still too much emphasis on funding so wrong suggestions are made.
- What happens to people after 25? Is 25 the new cliff edge? Not enough joined up thinking from all departments.
- There needs to be more forward thinking on young peoples' futures as expectations are not high enough for them.

- Carers who are paid to look after young people should be monitored more closely on their caring role, if they are under-performing or not engaging with the young people who they are responsible for. There should be a mechanism for the public to report them if they observe incidents. Action should then be taken against them
- OTs, social workers, SEN case officers and CAMHS should spend a few days at a “boot camp” so they can identify and learn empathy.
- People often do not know about things that are in place and find out by accident.
- Parents are relied on for pulling everything together to get their child/young person’s needs met.
- People should be listened to more instead of a box ticking exercise being used.
- There is little provision for people who fall between SLD and MLD. Very little progress made in 6 or 7 years spent in secondary schools.
- One parent is very happy with the Adult Social Services which was much better than Children’s.
- Schools are inspected but colleges are not and therefore are not accountable to anyone. Parents should be involved in these and be able to give feedback rather than relying on the students to do this.
- It is annoying to be re-referred to all services from childrens to adults and is a waste of money and paperwork. There is a disconnection between finishing childrens’ services and starting adult services.
- There is one 16 year old at Carew Academy who is bored and not challenged educationally. She feels that they are only providing a babysitting service.
- There are funding issues at Nescot and no homework is set for special needs people at college.
- Lower ability kids are given teachers with less experience of special needs and they should have better teachers.
- No advice has been given for post 18 youngsters and they do not know what provision there is for housing and employment.
- Mencap is very good and provides a wide variety of services. It also offers an employment service.

- All youth clubs finish at 18 or have been closed down due to lack of funding so there is no opportunity to socialise with a peer group. More resources are needed for this.
- An annual health check should be triggered by a reminder from the GP in order to stay as healthy as possible. You often have an annual appointment from paediatrics but are then discharged from the service. You still need a health check when you are adult despite the assumption that you don't.
- There is no safety danger training and travel training, although very good, is not offered to everyone. If you don't know about this how can you access the service? If this was offered more money could be saved by the Local Authority in travelling costs. Quite often a travel buddy would be fine for a week or so.
- When the young person reaches 18 there is no platform for support in seeking employment.
- Young people are encouraged to join in activities through Jigsaw and Smile. One young person gets paid for doing mystery shopping which is a result of joining in these activities. However, some young people do not want to join in these activities.
- Early Years provision is very good.
- SIAS/NAS/SPF Support groups are also good.
- Muschamp have better communication involving parents with EHC plans, allowing parents to ask questions.
- GPs are not prepared to help/signpost and need further training is needed in social prescribing rather than giving out pills
- Peer/parent support is good in specialist schools, however it is not so good in mainstream.
- There are coffee mornings in some schools, including Muschamp, but not all.
- Year 9 planning process is not starting when it should and there is no help.
- Education input from schools is usually very good in EHC plans but there is no help in the health and social care part of the plan.
- The Local Authority do not listen to you until you take legal action against them. Parents do not have a voice.
- We want a meaningful long-term service that meets our young peoples' needs.

- Delaying tactics are used to delay funding for successful outcomes. Children with severe disabilities or known disabilities should be fast tracked through first EHC plan assessment process.
- The decision makers are invisible and no-one knows who is on which Panel. There is a lack of partnership, communication and transparency with parents.
- Some parents are not engaged or represented at meetings because they are so tired from caring for their disabled children and battling with the Local Authority. They have spoken out previously but nothing has changed so they are totally deflated.
- Caring for a profoundly disabled child in Sutton I feel we are marginalised and do not have a voice. Decisions are made without knowing the needs of their children, their family, parents and siblings of children with disabilities. Respite for my child is for him not me.
- People fall off a cliff when entering adult services.
- You need energy to keep fighting which effects parents' mental health and the ability to care for their children.
- In Sutton the focus is on managing the budget rather than the needs of the child or family. One size does not fit all!
- A more holistic approach to assessing the needs of the child and family is required.
- There is a lack of Educational Psychologists to re-assess children when necessary and parents need to request this.
- There is a lack of youth services in Sutton and you are limited to activities you can access ie activities for health and wellbeing is limited.
- The last accessible soft play area was at Westcroft and was removed when this was redeveloped. There is no session incorporated there for Special Needs children.
- A multi-generational playground is needed in Sutton as there is already one in Merton.
- Short breaks are not linked to the family. "You only get a break if you break!"

- The expectation in Sutton is for parents to take their disabled child on holiday regardless of their disability and mobility. This is so exhausting that you need another holiday to recover.
- There is very little provision for children with profound needs.
- Carers have nowhere locally to take young people, especially if they do not drive.
- Beddington Park needs key access toilets and families with SEN need to be able to input their needs at the early stages if the park is to be redeveloped.
- Girls with ASD need specific assessments as diagnosis is very difficult and is usually too late. By the time they provide for education, they are often out of it and in some cases their mental health has been affected.
- Schools in borough do not replicate services out of borough schools provide, therefore outcomes are not being met in borough.
- Parents are unclear about healthcare needs and education funding. Education and healthcare do not have equal standing as more emphasis is based on education, whereas health and social care is just as important.
- There is no such thing as participation in Sutton. What is participation? Young people don't have a voice. They are not listened to. Parents are often not involved in key areas. They find out on a need to know basis.
- An education need requires definition to enable forward planning.
- Some schools have excellent SENCOs which ensure good educational outcome but this dependent on staff delivering them.
- Peoples' experience of CAMHS have been varied. Provision of CAMHS needs to be consistent as it is "luck of the drawer" if you get a good service.
- There is a range of disabilities in Sutton so the Local Authority need to arrange to engage with parents across the board.
- The support at college is not as effective as at school. You are better informed by the school system than the college system.
- Sherwood Park school has improved since the change of Head Teacher.
- A desirable outcome is Listen, Hear and Act!

## Saving the SCILL Centre Building

The SCILL building needs to be kept in use for people with disabilities for a number of reasons.

- Outcomes for independent living, health will be improved.
- Support Centre in Central Sutton needs to be used for families with SEND as it is purpose built for disabilities.
  - There are only 2 hoist/changing facilities in Sutton, one of which is SCILL.
  - There is a gym for those who cannot access mainstream services which will reduce isolation and improve health.
  - The building could be used for travel training.
  - Youth clubs are closed therefore youth clubs for SEND, Cyp can run from here for all disabilities as there is wheelchair and hoist facilities
  - Transition could be supported here.
  - The building could be used to improve outcomes ie work in café/enterprise schemes (Sherwood Café).
  - The building could be used as a group based setting such as holiday clubs.
  - The voluntary sector could fundraise ie.SPF for ball pool.
  - It is somewhere to go rather than walking round the shops.
  - It could be somewhere to meet for other parent/carers.
  - Parent/carers could have treatments there.
  - There is parking facilities at SCILL.
  - It would help Cyp to access their local community.
  - Do not allow the same thing to happen as the redevelopment of Westcroft and listen to all needs to improve outcomes
  - Can there be a non-inclusive leisure centre purely for SEND?