

Review of Support for Parents and Carers of Disabled children with SEN

My experiences as a service user (I am a parent of a disabled child) is not favourable.

I have a son who is now 13 and was diagnosed with Aspergers Syndrome (a form of Autism) in October 2010.

The support I have received from the local authority is minimal to say the least.

After the diagnosis I received some support from a Contact a Family Worker Blagoye Vucinic at Sunshine House.

As a family we also attended a workshop called the 'Help' programme facilitated by NAS (National Autistic Society) and in January 2011 attended a series of workshops facilitated by Parent Partnership called 'Earlybird'.

But my main criticism stems from the SEN team when it comes to issuing a statement of special need, it is only now that my son is receiving a statement, and yet I am still dissatisfied with the process as it takes too long and my son has since been permanently excluded from secondary school. I am sure that if the correct support mechanisms were in place in the first place this would not have been the case.

I also have a major concern as the statement was issued without his diagnosis this is just not good enough and shows the general lack of consistency and professionalism that is shortcoming within this department; it simply is not good enough.

The practical and financial resources available to me consist of benefits like DLA and Carer's allowance, I receive no financial aid from the borough and I am unsure what I am entitled to.

The knowledge and skill that I have up to know has been acquired from being a member of National Austistic Society, I receive their newsletter which keeps me informed and up to date. I am also a trustee and active member of Southwark Parent Carers.

My experiences of parenting a disabled child has been fraught difficulty and blatant discrimination especially with regards to my son's education. As I mentioned previously he was diagnosed a year ago, but once he was diagnosed everything changed. The school did not know how to deal with his behaviour and more or less labelled him as a difficult child. And since he did not have a statement of special needs was regularly excluded from school or had to endure internal exclusion in an 'isolation' room.

We have been to the school numerous times with Blagoye and he has even offered to train staff at the school but this has not been acted upon.

I have my suspicions also that my son has been bullied, but he will stick up for himself and is very often seen as the aggressor. Things have broken down irretrievably between us and the school and are looking for another school. Which is tricky because no one within the SEN team at Southwark can advise us on a 'suitable school with a good SEN and appreciates and has adequate provision for an autistic child'. It has been a logistical minefield to find information and advice about the best thing to do. It is very frustrating.

What has also hampered our progress is my son now has a statement with 15 hours of support yet his proposed statement came without his diagnosis of Asperger's Syndrome.

I am presently in the process of meeting with Yvonne Ely to rectify this, as it simply is not good enough.

Caring for my son is very difficult he has certain peculiarities and finds new situations very daunting, he is now more challenging as he is now a teenager and going through his own transition. This has been a very emotionally charged time for us all.

Family life is very chaotic I am not working at present, but most of my time is spent pacifying my son, coaxing and pleading with him to get up and be ready to go to the centre where he is receiving school support from 10-3 at Salmon Centre. As he is high functioning he needs a lot of stimulation, fortunately he loves reading which is a bonus, especially in the initial first weeks of his inclusion he did not mind going to the library.

I had to give up my part time job last year January after six months, simply because I could not cope with the school constantly phoning me telling me about my son's behaviour. I was making lots of mistakes due to lack of concentration and the simple fear of foreboding expecting the phone to ring with some more bad news about my child, It left me feeling pretty distraught and emotional.

I try to remain upbeat and positive, and I try to maintain some form of physical exercise when I can.

I walk most places or use the bus, I have a driving licence but cannot afford to buy a car. The exclusion has really stressed me out, as I cannot sleep for thinking of the worse case scenarios for the Governors meeting on 31 October, I just want that day to be over with.

