

Birmingham Special Education Needs and Disability (SEND) Services Survey

Healthwatch Birmingham welcomes the opportunity to respond to 'Birmingham's SEND Survey'. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care.

We welcome that stakeholders (Birmingham City Council, Birmingham & Solihull CCG, Birmingham Children's Trust and Birmingham Community Healthcare NHS Foundation Trust) in Birmingham are working together to review and understand SEND users experiences. Especially in ensuring that these experiences inform the development of a new SEND service.

Over the year (2018), Healthwatch Birmingham has listened to service users, the public and carers experiences of accessing health and social care in Birmingham. Regarding SEND services, we have heard concerns on lack of early intervention, poor follow up support following assessments; lack of clarity on EHCP forms on who delivers particular aspects of care; long waiting times to get EHC plans completed; delayed referrals by GP; failure to diagnose appropriately etc. Below are some excerpts from the feedback we received:

*My friend has an autistic child who is 5 years old, and I am also a support worker. I've witnessed how after the initial diagnosis, it is **very difficult to get any support at all. There isn't much emphasis on early intervention and services do not work together in a consistent way. There isn't clear responsibilities when the EHCP forms are being filled, or consistency in how practitioners use them. There should be a universal form that clearly marks who is going to deliver service and how it is going to be provided. It shouldn't be possible for professionals to just copy and paste text in the form.***

I have an autistic child and very bad experience with the service provided by Birmingham's local authority. At this service there is one particular professional who isn't doing her job. It took us seven months to get our son's EHCP completed and this was a fast turnaround. During the seven months I had to constantly be chasing the professional only to be told they are not in the office or on annual leave and there was no one else to deal with our son's EHC-Plan. This caused us to be extremely stressed out as we were panicking that because of the delay of getting the plan our child would miss out on his first year of education in a special school. Some of our friends children actually ended up being home schooled as they haven't got the plans or there was a significant delay. This is really painful as all the specialist support offered at special schools is crucial for the children. A full year without support and education can really set children & families back and this is all because of bad service by local authority. In addition,



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some parents have received the EHC-Plans with wrong child's information. This is a data breach. I don't know why something isn't done about it.

I have a 12 year old daughter who has ADHD and is on the autistic spectrum. I found ten cans of aerosol under her bed in January and took her to GP to discuss this as it was obviously very concerning. The GP just checked my daughter physically and said that she is fine. I had to then take her to A&E on another occasion as I found another can. They did a safeguarding referral to drug counselling. Finally 8 weeks ago a specialist took my worries more seriously and referred her to dermatology. They thought she applied aerosol directly on her skin as she has a sensory issue. Only through this we recently got autism diagnosis. I feel that if the GP had asked us more questions and had more answers of autism we could have got help much sooner. We are still waiting for CAMHS referrals as apparently we have to ask the school to do this.

I am unhappy about the diagnosis I have received for my child, as it's preventing them from accessing the support services needed. How can I challenge this?

My son has recently gone through an assessment of his autism needs through the local authority. I am unhappy with the outcome, as I do not believe that the result of the assessment fairly reflects certain aspects of my son's requirements, particularly around his communication with others. My son is currently seeking to leave home and I do not believe the support being offered will be appropriate. How do I get a review of the assessment from the local authority?

The feedback above demonstrates that service users, carers and the public have concerns about the quality of services provided by SEND. There is a real struggle for some carers to get the support they need for their children and most crucially problems with early year's intervention. Other quality issues have been around effectively identifying children's needs and ensuring that those needs are met. Another concern has been the lack of timeliness of EHC plans. This has meant that there is a delay in accessing the necessary educational provision leaving some parents to home-school their children. There appears to also be problems with people understanding the processes around the local offer. In many of the above cases, Healthwatch Birmingham had to send out information on the EHC process including statutory waiting time, how to challenge assessments, how to complain about staff conduct and information around the referral process.

Healthwatch Birmingham has also received the following feedback that highlights key issues carers and service user's face when they access some SEND services.



There is a paediatrician that comes to our child's special school. Our son is autistic and needs help. He is very intelligent and with this support could thrive, but I feel this doctor has just written him off as a child with a disability. If paediatrician would look at him as a person who can make a contribution in society it would make a big difference. My child is not just someone who needs constant support he could also contribute.

My 7 years old son is autistic and needs help for anxiety. He was referred to forward thinking Birmingham by his special needs school paediatrician. However when we had the appointment at FTB they didn't do anything. They just referred my son back to the school paediatrician. All I wanted was a referral to an occupational therapist. My son needs help with his anxiety before it develops into something worse. It's now been one year and he hasn't received any help. In the end I just gave up there is something wrong with the system.

My son has been discharged twice from the speech therapy service even though my child is not verbal. The service is also very poor in working with parents and teaching them how to help their children. They should do a workshop for parents to teach us what to do then we can learn how to help our children to speak. I have been able to find services that can help my child and I have been able to access these services because I am a proactive parent and educated. But other parents and people I know are unable to get any help and are missing out because of lack of information and help. This is especially difficult for people new to the country with no English. They do not know where to get support when they have children with support needs. My neighbour is new to the country and has a child with autism, and I had to help her on where she could get support.

When my daughter was 3 her nursery turned her down because of her behaviour. Health visitor was wonderful and helped us to get diagnosis for autism. However this process took a long time, over 6 months. Paediatrician at Allen's croft health visiting team was great but we only saw him once. The health visitor or staff at Allen's croft never told me that I may be able to get support from social services. I think what we need more is people teaching people, like speech therapist helping parents. Then we can help our children. Peer support and information is missing. I am ok as I can do my research, but what about those who can't. Health visitor could have told me about social services support.

This feedback shows the gaps in information that families need in order to support their children from accessing health services, knowing the right services to access, accessing social service support, and support with information/training on how to support their children. This feedback also highlights important considerations that need to be taken in order to understand and tailor support towards different groups in Birmingham such as those with language barriers.

Healthwatch Birmingham would like to see the following:



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08/11/2018

- Develop a strategy for communicating with family and friends at different points of their journey from pre-accessing services right up to when they have accessed services and ongoing support.
- Consider how there can be better integration between health, social care, and the education system.
- Develop ways of collecting continual feedback from friends and family to ensure that SEND services support their needs and are person-centred.

Throughout the year carers have expressed two key issues regarding communication and engagement:

- They told us that there is a lack of information available to support them in their role as a carer - *“I wish I had had more information about what to ask and what my/our rights are to make more informed decisions.”*
- They told us the lack of information and support across health and social care made them feel isolated and impacted - *“How am I supposed to know what I want if I am not being told about it?”*

Yours Sincerely,



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