

Birmingham Children's Trust - Friends and Family Support Survey

Healthwatch Birmingham welcomes the opportunity to respond to Birmingham Children's Trust 'Friends and Family Support 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 Birmingham Children's Trust is engaging with friends and families on their experiences of accessing support services. Especially in ensuring that these experiences inform any improvements or changes planned around these services. We also note the Trusts plans to incorporate the views of young people and their families into the development of new support groups.

Although, the feedback we present in this response is not on the support services this survey concerns, it however highlights the key areas the Trust needs to consider in developing new support groups. Over the past year (2018) we have heard the following feedback from families:

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



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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 the Trust needs to take 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 Trust do the following:

- 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 it can work in an integrated way with other health and social care services through these support hubs so that support is looking at the whole person.
- Develop ways of collecting continual feedback from friends and family to ensure that services provided at these hubs support their needs and are person-centred.

Throughout the year carers (friends and family) 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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