

Birmingham Children's Hospital: Harry's story

Harry is thirteen years old and has epilepsy as well as low functioning classical autism. Harry is non verbal and needs help going to the toilet. His behaviour can be unpredictable and if upset he can become violent.

Harry has attended Birmingham children's hospital for many years. His family used to find visiting the hospital extremely difficult as most of the hospital staff did not understand severe autism and how it affects people.

One common problem was being given hospital appointments in the middle of the morning which meant Harry had a long wait before getting to see the doctor. His mother felt uncomfortable asking for him to be seen quickly as she did not want people to think she was trying to push to the front of the queue. However, having to wait a long time would trigger Harry to behave in an extremely challenging way - sometimes hitting out at staff or other patients.

Once they got to see the doctor it was difficult for his mother to have a conversation with him as she always had to keep an eye on what Harry was up to

On one occasion Harry had to be kept in hospital overnight. The Hospital staff did not realise that he would need his own room for other people's safety as well as his own. As the hospital could not provide a single room his parents had to take him home, even though his condition was supposed to be monitored through the night. They knew that it was impossible to stay on a general hospital ward, even if they were allowed to stay with him.

Their experience of visiting Birmingham Children's Hospital has dramatically improved, with the help of Raj Jhamat, the hospital's learning disability nurse.

After they first made contact with Raj she visited them in their home to meet and get to know Harry. She also helped them fill out a care plan for Harry as well as a hospital passport.

How the families hospital experience improved

Now when Harry visits the hospital, Raj meets them at the hospital entrance and accompanies them around the hospital. She liaises in advance with hospital staff to help make Harry's visits go more smoothly.

Outpatient appointments are arranged at the beginning of clinic, so Harry does not have to wait long to be seen. Raj understands and is used to working with children with severe autism and spent time getting to know Harry. She sits in with the family when they see the doctor, helps facilitate conversation and at the same time keeps Harry engaged in activities, to prevent him from becoming distressed. If he starts to become agitated she will take Harry outside to play. This helps his parents feel less rushed, and able to have a meaningful conversation with his doctors.

When Harry has a seizure he often has to go to hospital A&E. The 'care plan' has been helpful as it lists all his medications and gives information about other medications that need to be avoided as Harry has had a bad reaction to them in the past.

His parents have found the hospital passport extremely useful. It includes information for hospital staff on how to avoid upsetting Harry such as not getting too close, not looking him in the face, speaking calmly and trying to divert his attention.

Harry's mother said:

'The hospital passport is amazing. It is simple, short and sweet and gets everything that needs to be said across in a very simple way. I don't just use it at the hospital - I use it everywhere I go, including school. It is so much easier to use this little book than the realms of notes that I used to carry around before.'

Case Study

You can find out about how staff at Birmingham Children's Hospital worked with parents, children and young people and the voluntary sector to improve the hospital experience for children & young people who have a learning disability - see www.cafamily.org.uk/pcp/success

This case study has been written to help parent forums work with commissioners and providers to improve local services for disabled children. You can browse more success stories at www.cafamily.org.uk/parentcarerparticipation

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