

Bristol Royal Children's Hospital – making a good service brilliant

Forum: Bristol parent carers

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Bristol Children's Hospital

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"I am hugely proud of the hospital and how they are working with parents' to bring about improvements. They understand how to build relationships and engage with parents to work with them. As a result of this we have seen real improvements the last two years."

Lou Paget, Parent Co-Chair , Bristol Parent Carers

Bristol Royal Children's Hospital has embedded the participation of parents into much of its work around children with disabilities, to improve the experience for patients and their families when attending hospital. Here are some examples of what they have been doing to achieve this.

Parents participation in decision making

Governing body and working groups

The hospital actively seeks views from parents representing a range of experiences, including parents of disabled children. Parents are invited to participate in working groups alongside health professionals, focusing on particular areas of work. Parents are also invited to give feedback on this work to the management team at board meetings. An example of this is the transition working group, which aims to improve the transition process when young people move from children's to adult health services. The hospital is involving parents and young people in developing pathways for different medical conditions, such as renal, cancer, and complex-needs patients. These pathways will aim to support a person-centred approach, focusing on the aspirations of the young person by working closely with their team from education and social care as well as health.

The hospital tries to make it as easy as possible for parents to be involved in both regular and one-off meetings and events. For example when the disabled children's working group meeting was scheduled to take place in holiday time,

the hospital arranged for a hospital play specialist to care for the parent representative's child, so she could attend the meeting.

The meeting schedule for the year is sent out in January, so parent representatives can plan which meetings they want to, or are able, to attend. Meetings are held during the school day, with the offer to cover expenses such as travel and parking. Parents receive all of the papers via email so if they can't attend a meeting, they can email comments to be included or catch-up with what was discussed from the minutes. For monthly, operational meetings, one parent representative usually attends but three times a year, there is an open invitation to any parent, carer or support organisation to join the advisory meeting, receive feedback on the work that has been going on, and to help set the agenda for the next quarter. In the remaining quarter, the hospital holds a family fun day away from the hospital site which includes patients and helps set the annual agenda. (See the Bristol Royal Children's Hospital Family Fun Day case study for more information on this).

The hospital also supports parent carer events in the community, providing speakers or information stands on the work the group is doing. This gives parents a chance to talk about hospital services and ask what to expect (sometimes before they have had to attend). This helps to manage parent carers' expectations and alerts them to the support that is available.

Interview panels.

When they recently interviewed for a specialist disability nurse, the hospital recruited the parent of a child with a learning disability to be part of the interview panel. The parent was very much an equal partner of the panel, asking questions such as, "What reasonable adjustments might be needed for a child who has a learning disability?" and how the nurse would work with parents who are "uncomfortable with providing medical interventions to their child."

Ward Inspections – the 15 step Challenge

The 15 step challenge is a simple way of finding out from patients and carers how to improve their hospital stay. Further information is available at: www.institute.nhs.uk/pro

[ductives/15stepschallenge/15stepschallenge.html](https://www.bristolchildrenshospital.nhs.uk/15stepschallenge/15stepschallenge.html)

The 15 step challenge involves a team of managers, nurses and parents visiting a hospital ward for an hour, (but not the ward they work on or where their child is a patient). The team spends one hour observing life on the ward, including how people are greeted, whether the ward is clean and the atmosphere in general. They talk to parents and children on the ward and ask them how they feel, how the staff have treated them and what they think would work better. This is a good way to capture views without parents having to make a big time commitment.

Parents would sometimes like to get more involved in helping the hospital to improve the way it works, but do not have time to become a member of a working group. Being part of the 15 Steps Challenge team means they can give a little of their time and help make quick improvements.

"I found the level of detail collected in the space of one hour incredible. It is a simple tool for involving parents and turning a good service into a brilliant one. We can pick up small environmental issues which can be very annoying – for example, a noisy lift which affected one bed, laundry bags being left in doorways, and parents not knowing where to go for food."

Parent member of the 15 step challenge team.

Improving hospital processes

Electronic hospital passport

The electronic hospital passport was developed with parents to help when children who have disabilities visit the hospital. Parents can download the passport onto their own computer, enter details about their child's condition and additional support needs and email it to the hospital. The passport is then made accessible on the hospital's computer so staff are informed about children's additional support needs. This also means parents do not have to keep repeating themselves to give this information. The passport is now widely used. You can read more about the passport and how it was developed in a separate case study the Bristol Royal Children's Hospital - computerised hospital passport

Disability nursing assessment checklist

Working with parents, the specialist disability nurse developed an assessment checklist for children who have a disability. This helps nurses gather additional information when a child who has a disability is admitted to the hospital. The hospital has a commissioning for quality and innovation (CQUIN) for completion of the assessment. This enables commissioners to link a proportion of funding to the achievement of local quality-improvement goals. Bristol Royal Children's Hospital has a CQUIN target that 95% of children who have a learning disability should be assessed within 48 hours. When the disability nurse post recently became vacant the hospital still managed to hit a high percentage rate, which illustrated that the process has become embedded into the work of all the nurses at the hospital

The assessment is a starting point for a conversation with the family to discuss in more detail the additional needs of disabled children or young people and compliments the routine admission assessment. Questions might include what care the parent would like to continue while their child is in hospital, when they might need a break, and what other services could offer support such as play or music therapy.

Improving information for parents – working with parents

The hospital involved parents in designing an information poster which is displayed on all wards. The poster suggests questions parents might want to ask nursing staff and encourages parents to ask them.

The hospital also consulted with parents, children and young people to find out what information they would like to find on the hospital website. Parent feedback included information hospital staff may not have thought to provide, such as where to buy a toothbrush or get food locally late at night.

Family fun days

Once a year, a family fun day is held for families of disabled children and those with long-term conditions. Parents can come and get information from hospital staff, including managers and ask questions. For children there are play, craft and music sessions as well consultation activities. Hospital managers also use this event as an opportunity to hear families' experience of visiting the hospital – both positive and negative.

You can read more detail about how the hospital does this in a separate case study, Bristol Hospital fun day

Going the extra mile

Supporting families whose children stay a long time in hospital

Having a child in hospital can be hard, especially if the child is in hospital a long time. Many children staying at Bristol Royal Children's Hospital live a long way away. In summer 2013, 80 sculptures of Gromit, designed by artists, designers and celebrities were put on display across Bristol. The hospital invited long-stay patients and their families on a bus tour of Bristol to see the 80 gromits, organised with help from the parent carer forum. They also sent invitations to parents of children in the cancer ward and neuro-rehabilitation ward at Frenchay Hospital, as their children's care transferred to Bristol Royal Children's Hospital in May 2014.

If a patient was not well enough to join in, the rest of their family were welcome to take part in the trip, including any siblings. This gave parents a much-needed opportunity to get away from the ward to meet other families and allowed patients to be included in the Gromit project. It also gave parents coming to Bristol from Frenchay an opportunity to meet staff from the hospital and be made to feel welcome. The hospital and the parent carer forum planned more joint activities for families prior to the transfer, to help them integrate into their new surroundings.

This is one of a series of case studies showing how parents helped improve health services for disabled children. You can browse all of these in our Success Stories section at

www.cafamily.org.uk/parentcarerparticipation

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