## NHS Parent Carer Participation Case Study

# Bristol Children's Hospital - computerised hospital passport for disabled children

Forum: Bristol parent carers Web www.bristolparentcarers.org.uk Email info@bristolparentcarers.org.uk

### Background

Bristol Children's Hospital previously used a document for children called 'All About Me' but nurses noticed that it was being used quite infrequently. Hospital staff said they thought the document was too long which meant they did not always have time to read it all. Families told us that they did not like having to fill in a new form every time something needed updating, as this was very time consuming. Families also did not like having to carry their child's passport with them all the time.

Nurses on wards noticed that parents of disabled children frequently stayed continually by their child's bedside. They wondered if ward staff could be doing more so families would feel confident enough to leave their disabled child with them, at least for a little while. For that to happen the nurses would first need to understand what additional support children needed.

#### What they did

Working with parent carer forums from Bristol, North Somerset and South Gloucestershire, the hospital developed a new shorter electronic passport adapted from a version originally developed by Gloucestershire NHS Trust. Families can download it from the web at www.uhbristol.nhs.uk/hospital-passport

Once parents have entered their children's details they can email it to the hospital where it is stored online, with the child's records. If parents want to update their passport they simply amend the document and resubmit it by email.

Whenever the children go to hospital and whichever department they visit, the information is available online to hospital staff. If a child is admitted, the ward clerk prints their passport to include in the child's notes at the end of their bed,

Parent carer forums helped in the development of the passport by:

- helping to design the form
- finding families to test the draft version of the form, to make sure the layout worked
- finding a small number of families to pilot the passport
- publicising the passport to families of disabled children.

#### **Bristol Children's Hospital**

**Web** www.uhbristol.nhs.uk/hospital-passport **Email** Claire.Tomkins@uhbbristol.nhs.uk

> For a hospital passport to be effective hospital staff need to know about it and use it. The lead nurse for disability at Bristol Children's Hospital found staff to publicise the passport in different departments. Other professionals at the hospital have been very supportive of the approach.

At the time of writing, 167 children have hospital passports stored online with Bristol Children's Hospital.

GPs' practices and schools have expressed interest in being able to access information on the hospital passport. The hospital is exploring the possibility of giving families the passport on a memory stick, so parents can easily provide the same information to other services involved with the care of their child.

#### Why this works

The information in the passport helps staff understand what additional support a family might need and how they might best assist them. It informs them about anything that might distress the child, so they can try to avoid this happening. It also alerts the hospital if a child is to be admitted who has very complex needs, so they can plan for this in advance of their admission.

The Hospital Passport uses a traffic light system. All essential information about the child is written in the red section. This includes method of communication, equipment needs and triggers that may lead to a child displaying challenging behaviour.

The amber section has information about the child's personal needs, such as feeding, toileting, ventilation, moving around and how they express emotions.

The green section is about what the child likes and dislikes, and what could be done to make their stay in hospital more comfortable.

Families like the electronic hospital passport as it a convenient way of sharing is information with different staff, which helps to make their visits to hospital less stressful.

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

Contact a Family 209-211 City Road, London, EC1V 1JN Tel 020 7608 8700 Fax 020 7608 8701 Email info@cafamily.org.uk www.cafamily.org.uk

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