Promoting the healthcare rights and needs of chidlren and young people

Guide to Engagement with Families – Handout B Examples of Engagement

(Session Outline 11.2 Let me count the ways - discuss examples and decide where to place them on the ladder of participation).

1. Different days and different times

Parents of children with complex healthcare needs were tired of having to attend numerous different appointments on different days and in different locations. They fed this back through consultation on the service and were able as a result to set up a one-stop shop service, where clinicians were all available on the same day and at the same place.

2. YP Hospital Services

A group of young people in a local authority co-terminous with the local health board formed a task force to examine how YP-friendly services were.
Following an audit of the local paediatric ward, they were able to effect changes to make this more age-appropriate for young people when mobile phones, comfy pillows and cooking facilities were introduced.

3. Hospital Passport

This came about when feedback from children indicated that they felt confused and out of control in the hospital setting not knowing what was happening and what was going to happen next. Children thrive with certainty not the reverse. A multi-disciplinary group including families developed the hospital passport to focus on their rights, give them some control and help them to manage their experience better.

Hospi Chill App has been built on the success of the Hospital Passport Coping Kit which was rolled out across Scotland in 2013 following funding from Glasgow Children's Hospital Charity. While the Hospital Passport had very successful outcomes for children under 12 coping with hospital anxiety, Hospi Chill has been developed as a digital resource to appeal to older children and teenagers.

During the development process of the app, Donnan spoke with a number of older children to ensure that the app was easy and fun to use with animation and audio. Using a number of rewards and badges, Donnan wanted to give the relaxation app a game-like feature to keep it fun and easy to use. She continued: "We wanted their feedback on how they would use the app, what information would be useful to include and their thoughts."

4. What Matters to Me (as opposed to What is the Matter with you?)

This is an initiative developed as a result of children not feeling involved in their care and messages containing important information about them not being passed on for example, a deaf child who needs her mother to act as interpreter.
Solution - every bed has a white board above it where the child is invited to write not ***what is the matter*** with them but ***what matters to them***. For example, they need help eating or their carer also acts as interpreter, they don't want to be wakened at 6.30am for a breakfast they cannot eat!

5. Healthcare Support in School

Following a short life working group convened by CYP Commissioner Scotland to look into the difficulties for children with complex healthcare needs experiencing barriers to these being met in school, the Scottish Government (SG) is reviewing the existing Guidance now more than 15 years out of date. The SG Guidance Review group is made up of 3rd sector organisations, patient representative groups and individuals across all sectors.

6. Education at times of illness or when too ill to go to school

Following concerns raised by families, professionals etc into the patchy inequitable provision for education in hospital or at home when not well enough to attend school, a FOI request revealed the extent to which this was either not known about or ignored. Patient groups and 3rd sector organisations persuaded the SG to revise the Guidance on the subject and raise awareness through relevant bodies such as Education Scotland. In collaboration with families, ASCS and Enquire (National Service for ASL) produced a factsheet to guide families, school staff and others in this area.

7. UNCRC 25th Anniversary

As a result of a suggestion made b a voluntary organisation member at the hospitals Rights of the Child group meeting, a children rights day to celebrate 25 years of UNCRC was set up in the hospital. This will be a multi-media, multi-faceted event to raise awareness of UNCRC and EACH all across the hospital with the eventual aim of service improvement for CYP and families.

8. ASCS Anaesthetics Survey

Families had expressed concern at not being allowed to be with their child when going for surgery most especially in the recovery room afterwards. Following a nationwide survey, awareness of the issue, more is being done to help parents support their child. This was shown to be particularly important when the child has additional needs such as ASD or ADHD.

9. ASCS Guides to Pain and Needles

Helping your child cope with Pain and Needles
ASCS, using information from stakeholders (children, young people, families, professionals) developed guides to assist children when managing painful procedures in hospital or during routine health care and dental treatments. The practical play-based ideas have been shown to be very effective in reducing pain, promoting compliance and speeding recovery and return home.

10. EACH Young People's Charter

ASCS is a member of the European Association for Children in Hospital (EACH) which has produced a charter of rights for children and young people's healthcare at times of illness.

We asked young people to come up with a young person's version of the charter in young people-friendly language. Through workshops and focus groups they worked on what each of the 10 charter points meant to them and produced sound bites for the speech bubbles as an overlay on the accompanying photographs.