Involving children and young people in specialised commissioning

Children & Young People Engagement team
RCPCH funded by NHS England
This guidance offers advice and tips, much of which comes directly from children and young people that use the services, about how they would like to be involved in specialised commissioning procedures.

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Introduction

Children and young people make up a significant proportion of the users of NHS Specialised Services. About 30% of emergency and urgent care activity relates to children and young people and 15% of children and young people have a long standing illness yet they rarely have a voice within decision making about these services at a national strategic level.

Children and young people have told us how important they think it is that they have a voice about services at the commissioning stage. They want a direct line of communication with Commissioners and Clinical Reference Groups; however they also want it to be inclusive, creative and flexible. A move to greater use of working groups within Clinical Reference Groups provides an opportunity for more creative and focused engagement of children and young people in Specialised Commissioning, yet challenges around resources and support still remain.

These challenges will require Commissioners and Clinical Reference Groups to work in partnership with parents, existing support groups and voluntary organisations and with the wider hospital based community of clinicians, play specialists, activity workers and hospital volunteers to maximize opportunities to engage children and young people in this work.

This guidance offers advice and tips, much of which comes directly from children and young people that use the services, about how they would like to be involved in Specialised Commissioning procedures. It highlights how children and young people can be engaged directly with Clinical Reference Groups but also looks at many other methods that children and young people have identified for them to have a voice at a strategic level.

Here are the key ingredients.

We want more choice and flexibility
Children and young people wanted to see a range of different approaches for different ages, abilities and interests (including more creative and interactive approaches). It was important that mechanisms to have a say include younger children, those that do not communicate verbally, those subject to the Mental Health Act 1983 (amendments 2007), and to accommodate periods of significant ill health. During times when their health is a factor, it may reduce or change the way children and young people engage, for example rather than attending events in person, they could contribute online (surveys, youth proofing, virtual conference calls).

It has to be flexible to reach the young people who are too unwell to attend meetings.

Young woman, Alder Hey Youth Forum

**We want to meet, talk and share experiences with other children and young people**

Children and young people who had used specialised services often talked of feeling quite isolated when they were unwell or there being stigma amongst their peers about their illness. Methods of engaging where children and young people got to meet others of a similar age with the same condition repeatedly came up as popular. Events, forums and groups provided an opportunity for peer support and a chance to make a difference - a winning combination!

**We want to feel like we are making a difference and be involved, not just consulted**

Children and young people wanted to get involved in activities where they could make a difference and help other children and young people who might be going through what they had experienced. Whilst questionnaires and surveys are commonly used, children and young people did not find them interesting or engaging and felt that they rarely knew how their answers were used. They wanted to engage in a process of dialogue and to see the impact of their involvement.

**Come and talk to us on wards, in waiting rooms and at support groups we already attend**

Children and young people who used specialised services often spent a lot of time in hospitals. As one young person put it “I have grown up here, it’s like a home” (young woman, Alder Hey Youth Forum).
The young people could see a lot of opportunities to engage whilst they were waiting for appointments or when they were in-patients and bored on the wards. They felt this was a good use of time as they had to be there anyway. This approach worked best when children and young people were approached first by someone they knew already to check if they were interested and feeling well enough to engage.

Younger children and those older children who found groups, meeting new people or different environments difficult were also more likely to open up and share experiences when in familiar surroundings. Partnerships with existing support groups are a great way to reach these children and young people.

I feel like that it’s actually a good thing for in-patients because when I was on the ward there wasn’t much to do during the day. In fact if no one came to visit me then I would just be on my phone and watching movies and stuff so there is a lot of dead time on wards, it just drags.

Young man, Teenage Cancer Trust Unit, UCLH

You would be stupid not to use it when you have a free group. Everyone is congregated in one place. You could invite other young people who have been discharged in.

Young woman, RCPCH &Us workshop

**Listen to parents and carers, but don’t only listen to parents and carers**

Many young people, especially the older members, talked about how they did not always share fully their thoughts and feelings with parents and carers as they didn’t want to worry them. Parents and carers also at times were feeding back young people’s experiences with the ‘parent filter’ on – highlighting the elements that they felt were important.

Working with parents and carers to listen to children and young people is crucial, however it is not the same as hearing from children and young people themselves!

**Just take 3**

Try these three steps to begin involving children and young people in your work.

1. Find out through the Clinical Reference Group members, particularly your Patient and Public Voice representatives, which organisations, local or national, are bringing young service users together. Contact them and add these groups to your Registered Stakeholder lists.
2. Make sure information about consultations goes out with ‘child friendly’ versions and actively invites responses from children and young people. Make sure consultation results can be analysed so you can see if a respondent is a child or young person service user.
3. Begin the discussion about opportunities for more creative engagement with your child
or young person service users at Clinical Reference Groups and with possible partners.

Find out more

For more information, practical tips and activities see the full Guidance on Involving Children and Young People in Specialised Commissioning below.

Downloads
Full report - involving children and young people in specialised commissioning.pdf 1.33 MB
Resources list.pdf 416.28 KB
Case studies.pdf 151 KB
And Us - Legislation briefing.pdf 228.63 KB