

Children and Young Peoples Outcomes Forum

Background Information for Parent Carer Forums

The Children and Young People's Outcomes Forum, is jointly chaired by Christine Lenehan (from the Council of Disabled Children) and Professor Ian Lewis (from Alder Hay Children's Hospital) and was launched on 26 January 2012.

The Government has asked the Children and Young People's Health Outcomes Forum to engage and hear views from children, young people, parents as well as those involved with their care.

The Forum's work will inform the development of the first ever Children & Young People's Health Outcomes Strategy to be published in the summer.

The Strategy will ensure that the outcomes measured are the ones that matter most to children, young people, their families and the professionals responsible for their care.

More information can be found at <http://healthandcare.dh.gov.uk/category/children/>

There is a working group on Long Term Conditions/Disability/Palliative Care who are looking at the 'journey' or Pathway that families usually find themselves on and will look at the **common key issues and challenges** along the way.

This group, which includes parental representation, identified the following steps as particular challenges or influences on the whole family:

1. Getting into the system

Finding someone to listen to your concerns, acknowledge them and start acting on them

2. Getting a quality assessment

Having needs appropriately assessed and that result in whatever interventions are needed

3. Getting a quality service

Having an appropriate, competent and co-ordinated team supporting the child and family

4. Transition

Transition into the adult world/adult care or Palliative Care (adult or child)

To help us progress with this very important work we would be very pleased to receive replies to any or all of the following sections. Please send to: helen.jones@cafamilly.org.uk

With many thanks, Anna Gill – Parent Representative, Children and Young People's Forum

**Possible Outcomes Measures for Children and Young People with Long Term Conditions
Disabilities and/or Palliative Care**

Getting into the health system	<ul style="list-style-type: none"> • What are the 5 Top challenges for the families of disabled children and young people? • What are the 5 Top changes that could improve things? • What are the 5 Top suggestions of how these improvements could be measured?
Getting a quality assessment	<ul style="list-style-type: none"> • What are the 5 Top challenges for the families of disabled children and young people? • What are the 5 Top changes that could improve things? • What are the 5 Top suggestions of how these improvements could be measured?
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Transition	<ul style="list-style-type: none"> • What are the 5 Top challenges for the families of disabled children and young people? • What are the 5 Top changes that could improve things? • What are the 5 Top suggestions of how these improvements could be measured?