## **NHS Parent Carer Participation**



## Making use of clinical guidance and standards

Commissioners have to consider clinical guidance, including guidance set by National Institute of Clinical Excellence (NICE) and the Royal College of Paediatrics and Child health(RCPCH) guidelines when commissioning services.

NHS England is developing a range of tools to support effective commissioning. This will include setting service standards, model care pathways, commissioning guidance and standard contracts which will all be based on what is written in clinical guidelines. (You can read more about NHS England in a separate briefing paper called *Clinical Commissioning groups and NHS England*.)

Parent carer forums might find these resources useful levers when in discussing services with managers and commissioners.

#### **Clinical Guidance**

National Institute of Clinical Excellence (NICE) clinical guidance recommend the standards of care patients should receive for a specific disease, condition or clinical area. When developing guidelines all the available research evidence is considered as well as the views of experts, patients and carers and the industry. These are lengthy documents but NICE also produce quick reference guides. (see www.nice.org.uk)

The Royal College of Paediatrics and Child Health (RCPCH) also develop clinical guidelines.

You can download NICE and RCPCH guidelines from the RCPCH website at http://www.rcpch.ac.uk/title-z

Guidelines which might be of particular interest to parent carer forum include:

- NICE: Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children young people and adults.
- NICE: Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum
- NICE: The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and

secondary care

- NICE: Spasticity in children and young people with non-progressive brain disorders: management of spasticity and co-existing motor disorders and their musculoskeletal complications.
- RCPCH: Chronic fatigue syndrome/Myalgic encephalomyelitis (or encephalopathy): diagnosis and management.
- NICE: Antisocial behaviour and conduct disorders in children and young people: recognition, intervention and management

# **Quality & Service Standards - coming soon**

Quality standards are a concise set of statements designed to drive and measure priority quality improvements within a particular area of care. They will be based on the best available evidence such as NICE clinical guidance.

Quality standards which are under development by NICE and might be of particular interest to forums when they are complete include:

- Attention deficit hyperactivity disorder
- Autism (children and young people)

### **Care Pathways**

Care pathways illustrate the care process for patients for specific conditions, from presenting with symptoms, through to diagnosis and treatment options. Some local area have already developed these working with families. Some examples of these can be seen at http://www.nbt.nhs.uk/cchp/clinicians/community-paedia-tricians-referral

The British Academy of Community Child Health (BACCH) are committed to developing a pathway approach to the delivery of services to children and young people(CYP) and their families. These will include condition and pathway specific standards, measures and a process to improve services. They are expected to be available in the next 12 months.

This is one of a series of briefing papers to help parent forums work with health commissioners and providers to improve local health services for disabled children. You can browse all of these in our NHS Changes section at www.cafamily.org.uk/parentcarerparticipation

If you would like to discuss this briefing paper in more detail, please contact Sheila Davies at Contact a Family on 020 7608 8773 or email Sheila.Davies@cafamily.org.uk

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

Incorporating The Lady Hoare Trust
Registered Office: 209-211 City Road, London, EC1V JJN
Registered Charity Number: 284912 Company Limited by guarantee
Registered in England and Wales Number: 1633333
Charity registered in Scotland Number: SC039169
VAT Registration Number: GB 749 3846 82