

# The Report of The Children and Young People's Health Outcomes Forum

## What does it mean for disabled children?

The recommendations of the Children and Young People's Health Outcomes Forum report focus on what the NHS needs to do to improve both children and young people's health outcomes and their experience of health services.

The key themes on which the Forum has made recommendations are:

- Putting children and young people at the heart of what happens
- Acting early and intervening at the right time
- Integration and partnership
- Safe and sustainable services
- Workforce, education and training
- Knowledge and evidence
- Leadership, accountability and assurance
- Incentives

The Forum has recognised that disabled children and young people are particularly disadvantaged compared to children and young people as a whole. To address the specific challenges facing disabled children and young people the forum established a group long term conditions, disability and palliative care sub group to ensure the Forum's recommendations will improve the situation for disabled children and young people.

The Forum has made a core recommendation that the NHS introduce four new overarching health outcomes indicators that can be built into the existing health outcomes frameworks. These health outcome indicators will drive improvement in the four areas that present the biggest challenges for disabled children and young people, and where things most often go wrong.

The four overarching health outcome indicators are:

### 1. Getting into the health, education and social care system

An indicator measuring the time taken from first NHS presentation to diagnosis or start of treatment

### 2. Getting a quality integrated assessment

An indicator for integrated care that will measure the contribution of all relevant services through a new composite measure

### 3. Managing transition

An indicator that will measure effective transition from children's to adult service

### 4. Getting a quality service

An indicator for age appropriate services for children and young people, with particular reference to teenagers

In addition to these new outcome indicators, the Forum's report makes a number of recommendations that will improve disabled children and young people's experience of the health system. These recommendations include:

- **Identification of children and young people with long term conditions and disability**

Improve the information that the NHS and schools capture about disabled children and young people, to support better identification and better commissioning of services to meet this need.

- **The voice of disabled children and young people**

Strengthen the voice of disabled children, young people and their families by extending all measures of patient experience to children and young people and creating a child health charter based on the United Nations Conventions on the Rights of the Child.

- **Making the system work**

Every level of the NHS must have clear strategic leadership for children and young people, to drive service improvement and integration of services for disabled children and young people, and where possible provide services closer to home.