

# Healthwatch, parent carer forums and disabled children and young people



## Why Healthwatch need to focus on disabled children and young people

Disabled children are a relatively small proportion of the population but can have complex needs.

Care for disabled children can involve several healthcare disciplines (at primary, secondary and tertiary level involvement) and other agencies including social care, education, housing, leisure and transport.

Reviews by both the Healthcare Commission (2008) and Sir Ian Kennedy (2010) found major problems in the provision of health services for disabled children.

**“children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need.”**  
Healthcare Commission 2008

The recent DH statutory guidance says Health and Wellbeing boards have to consider the needs of, children and young people with special educational needs or disabilities in their joint strategic needs assessments (JSNA) and their joint health and wellbeing strategies (JHWS).

The mandate from the Secretary of State to the NHS England (previously NHS Commissioning board) mentions the need to develop partnership working across different services, to:

- support children and young people with special educational needs or disabilities, and
- demonstrate progress against the government’s priorities of continuing to improve services for both disabled children and adults.

## How parent carer forums can support the work of Healthwatch

In most local authority areas there is a parent carer forum, whose membership is made up of parents of children with a range of disabilities and conditions. Unlike other support groups, the primary aims of parent carer forums are to work in partnership with service providers and commissioners to improve the services their children access across health, education and social care.

Parent carer forums help identify and feed back problems frequently experienced by disabled children and young people accessing services. Some parents take a more active role, and work directly as a representative of parents in the local area on strategic decision-making boards, or ‘task and finish’ groups.

Parent carer forums began to develop in 2008. Involving parent carer forums in commissioning local services was shown to be key to developing services that met families needs and made best use of resources. The evidence of this was so strong that in 2011 the Department for Education agreed to continue supporting and funding parent carer forums for a further four years. This included funding the National Network of Parent Carer Forums (NNPCF), which brings together information from forums across England and works directly with the Department for Education and Department of Health.

Parent carer forums can provide specialist knowledge of the wide range of services their children access and insight into how services can be better integrated across health, education and social care. They are well-placed to help Healthwatch collect both quantitative and qualitative evidence to feed into the JSNA and JHWS. They could also help Healthwatch reach disabled children and young people so their views are heard.

Finally, examples of how forums have brought about improvements in services could motivate other community groups to get involved and do similar.



Working with



## How Healthwatch can work with parent carer forums

Parent carer forums vary from area to area. Some are very strong, well established and experienced whereas others are relatively new and less well established.

Each Healthwatch and parent carer forum will need to explore how they can best support each others work, taking into account their own local situation and capacity. Meetings and events must be planned to take place at parent friendly times. This is especially important for parents working as volunteers, whilst juggling a range of parent and carers commitments.

Healthwatch might be able to support the work of parent carer forums by:

**Information requests:** commissioners and providers of services have to respond to requests for information from Healthwatch within 20 working days. This can be a useful way to help parent carer forums get supporting evidence to commonly reported problems.

**Consultations:** some forums will be happy to run their own focus groups or surveys to gather parents' experiences and write reports to send to managers and commissioners. Others will have less capacity and would be grateful for assistance with this when it is possible.

**Finding contacts:** parent carer forums sometimes struggle to find the appropriate service manager and/or commissioners to have a dialogue with. Healthwatch might help them make this initial contact.

**Inspections:** Healthwatch can ask parent carer forums about any concerns to local families of disabled children, to inform their own inspections of services.

An example of how Healthwatch and parent carer forums might work together can be seen in a case study which shows how Peterborough LINK worked with their local parent carer forum.

**Family Voice Peterborough: Hospital and hydrotherapy - working with and independently of their Local Involvement Network (LINK)** - can be downloaded from [www.cafamily.org.uk/pcp-case-study-peterborough](http://www.cafamily.org.uk/pcp-case-study-peterborough)

### Getting in touch with your local parent carer forum

In most local authority areas there is a parent carer forum, Contact details of local parent carer forums can be found on the Contact a Family website at [www.cafamily.org.uk/parent-carer-forums](http://www.cafamily.org.uk/parent-carer-forums) and on the NNPCF website [www.nnpcf.org.uk](http://www.nnpcf.org.uk)

### Find out more about parent participation

You can read about how parent participation has improved services by going to [www.cafamily.org.uk/parentcarerparticipation](http://www.cafamily.org.uk/parentcarerparticipation)

### Contact a Family [www.cafamily.org.uk](http://www.cafamily.org.uk)

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of their disability or health condition. Contact a Family is also funded by both the Department for Education and the Department of Health to support parent carer participation in England, working in partnership with the National Network of Parent Carer Forums (NNPCF).

**contact a family**  
for families with disabled children

### National Network of Parent Carer Forums [www.nnpcf.org.uk](http://www.nnpcf.org.uk)

The National Network of Parent Carer Forums (NNPCF) is made up of all of the parent carer forums from across England. The NNPCF ensures that local parent carer forums are aware of national developments and promotes opportunities for the voice of parent carers to influence at a national level. The NNPCF works closely with the Department for Education, the Department of Health, and other partner organisations to improve outcomes for children and young people with disabilities or additional needs and their families.



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