

For more information about working with other parents to use of the NSF to change the way services for disabled children are delivered please refer to Contact a Family's accompanying guide, *Making a difference: How parent groups can use the children's NSF to influence local services*.

For the latest on influencing health services from Contact a Family visit [www.cafamily.org.uk/influence.html](http://www.cafamily.org.uk/influence.html).

For more information about accessing services for your child, for general support and information or to find a local or national support group get in touch with the Contact a Family freephone helpline.

Helpline 0808 808 3555 (Mon–Fri, 10am–4pm)

Minicom 0808 808 3556

Email [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

Web [www.cafamily.org.uk](http://www.cafamily.org.uk)

Postal address  
Contact a Family  
209–211 City Road  
London  
EC1V 1JN

Funded by the Department for Education and Skills

# Making a difference

## the NSF and parents of disabled children





## What is the National Service Framework for Children, Young People and Maternity Services?

National Service Frameworks, or NSF's, set national standards and identify key treatments and services for particular groups of people, e.g. people with coronary heart disease, older people, etc. Since Autumn 2004 there has been an NSF for children and young people.

Currently the quality of the health and social care services experienced by disabled children and their families around England is variable. The government has recognised that services need to be improved. The result is the National Service Framework.

The National Service Framework is the government's ten year plan to improve services for children. It applies to health and social services but also involves education services. The aim is to develop services which are based around the needs of children and their families instead of focussing on the needs of the organisations delivering the services.



## What does this mean for you and your disabled child?

The Children's NSF is a hugely important new step from the government. It is the first time that national standards have been set for health and social care for children. Meeting these standards will involve a great deal of change for health, social and education services. These changes should take place over the next ten years. By 2014 service providers must have met the standards set out in the NSF. How this is done and what is prioritised will depend on the local service providers and the needs of the families in the area.

The result of this should be that services are co-ordinated better and staff from different services communicate and work together for the benefit of children and families. Service providers will also be inspected regularly. If they are not meeting the standards they will fail the inspection.



This is good news for any parent. For parents of disabled children, the existence of a specific standard covering the needs of disabled children and young people means that the standard of care and services they receive must improve. It also gives the parents of disabled children a significant tool with which to influence services and ensure progress is made. The quality of services outlined in the NSF can be used to measure the quality of the services you are currently receiving. For more information on this see the accompanying guide 'Making a Difference: the NSF and parent support groups'.



## Who does it apply to?

The NSF covers services for all children up to the age of 19. Within the NSF there are 11 standards covering different aspects of service provision for children. (For a full list of the standards see the end of this leaflet.)



## The standard for disabled children

This standard says: ‘Children and young people who are disabled or who have complex health needs, receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.’

This covers a wide range of services and care.

Each standard in the NSF contains markers of good practice. These are the aims that service providers should be working towards to improve the services they offer to children, young people and their families. The markers can also be used to measure the progress made by service providers.



## If you are not happy with services

Although the NSF is not law, it is government policy which must be followed. Service providers must aim to meet these standards when they are planning and delivering services for disabled children and their families. As a parent, if you find that a service provider is not following the NSF you will be able to make a formal complaint.

If you are unhappy with the services you are receiving and would like to speak to someone about this please ring the Contact a Family freephone helpline. Our Parent Advisers will be able to talk you through possible courses of action. The helpline is open Monday to Friday, 10am to 4pm on 0808 808 3555.



## Markers of good practice for services for disabled children

- 1 Disabled children are able to access all mainstream children’s services. Service providers work to include disabled children in childhood, family and community activities.
- 2 Different service providers work together to provide a child-centred service for disabled children and young people. This starts at the point a child is referred and continues through a diagnosis being made, when a child is assessed for services and then when those services are provided.
- 3 Children’s disabilities are identified early by practitioners making use of the government’s assessment procedures. After diagnosis services are provided which best support the child’s physical, cognitive and social development. These services should be provided as early as possible with minimum waiting times.
- 4 If disabled children and young people need ongoing health care this is delivered by members of staff who have the right skills for diagnosis, assessment, treatment and ongoing care and support. The care given should be of high quality and evidence based.
- 5 Families are offered a range of appropriate family support services that are flexible and responsive to their needs and that promote their inclusion in the local community. They should be told about the option of direct payments helped to make use of this if they choose.

- 6 Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support. They are also invited to be involved in opportunities to shape services.
- 7 Area Child Protection Committees (Local Safeguarding Children Boards) have strategies and codes of conduct to make sure that disabled children and young people are safeguarded from emotional, physical, sexual abuse and neglect. These procedures should be based on the government document Working Together to Safeguard Children.
- 8 Multi-agency transition planning and services focus on meeting the hopes, ambitions and potential of disabled young people. This includes maximising inclusive provision, education, training and employment opportunities.
- 9 A range of flexible, sensitive services are available to support families affected by the death of a disabled child or a child with a life-limiting illness.

*A good way to measure whether your area is meeting the standard for disabled children is to check your experience of the service against these markers.*



In the first instance, you should also speak to the staff providing the services with which you are unhappy. If necessary refer to the guidance in the NSF.

You could also contact the Patient Advice and Liaison Service (PALS) in your NHS Trust. PALS provide information, advice and support to help patients, families and their carers. To find out where your PALS office is ask staff at the hospital where your child receives care. You can also find out by phoning NHS Direct on 0845 46 47.

Another way to make a difference is to get involved with a local support group for parents of disabled children. By working together the impact you are likely to have on services will be greater. For more information about how a local group can get involved see the accompanying guide 'Making a Difference: How parent groups can use the children's NSF to influence local services' available from the Contact a Family helpline.



## Other standards in the Children's NSF

Standards 6 to 10 are designed to be read in conjunction with the core standards (1 to 5) which apply to all children. Other standards may be relevant to you and your child, for example:

- **Standard 6** if your child is ill
- **Standard 7** if your child is spending time in hospital
- **Standard 8** if your child has complex needs
- **Standard 9** if your child's disability has a mental health element

For information on all the standards in the National Service Framework for Children, Young People and Maternity Services click on [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/fs/en)

or to order copies by phone  
 Department of Health Orderline  
 Tel 08701 555455  
 Minicom 08700 102870  
 Email [dh@prolog.uk.com](mailto:dh@prolog.uk.com)  
 Quote the order numbers for the standards you would like.



Standard	What it covers	Who they apply to
Standard 1	Promoting health and well-being, identifying needs and intervening early <i>Order no. 40493/Core Standards</i>	These standards apply to all children and young people
Standard 2	Supporting parenting	
Standard 3	Child, young person and family-centred services	
Standard 4	Growing up into adulthood	
Standard 5	Safeguarding and promoting the welfare of children and young people	
Standard 6	Children and young people who are ill <i>Order no. 40486/III Child</i>	These standards cover services for particular groups of children and young people
Standard 7	Children and young people in hospital <i>Order no. 30352/Hospital Services</i>	
<b>Standard 8</b>	<b>Disabled children and young people and those with complex health needs</b> <i>Order no. 40494/Disabled child</i>	
Standard 9	The mental health and psychological well-being of children and young people <i>Order no. 40492/Child &amp; Adolescent Mental Health</i>	
Standard 10	Medicines for children and young people <i>Order no. 40487/Medicines</i>	Maternity services
Standard 11	Maternity services <i>Order no. 40498/Maternity</i>	

