



## COT/ BAOT Briefings

### National Service Framework for Long Term Conditions with relevance to children and young people

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#### 1 Introduction

The *National Service Framework (NSF) for long term conditions* (Department of Health 2005a) will be implemented over 10 years. Although the focus is on adults with neurological conditions much of it applies to anyone with any long-term condition.

The NSF takes account of other relevant NSFs, including the NSF for *Children, young people and maternity services* (Department of Health) and aims to build on proposed changes in NHS management and commissioning to bring about a structured and systematic approach to delivering treatment and care for people with long-term conditions. It should be read alongside *National Standards, Local Action: The Health and Social Care Standards and Planning Framework 2005/6 – 2007/8* (Department of Health 2004a), which promises consistently high standards of NHS care across the country, *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration* (Department of Health 2005b) see COT Briefing no.35.

The full National Service Framework (NSF) can be found at:

[www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4105361&chk=jl7dri](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4105361&chk=jl7dri) accessed 29/03/2006

*COT Briefing no. 36 National Service Framework for long term conditions* can be found at:

[www.cot.org.uk/members/publications/free/briefings/pdf/36LTC\\_NSF.pdf](http://www.cot.org.uk/members/publications/free/briefings/pdf/36LTC_NSF.pdf) accessed 05/05/2006

For young people the NSF highlights the importance of transition planning, in terms of moving from children's to adult health services, to ensure continuity of services and support through the necessary changes. It also states that young people could become expert patients, which is part of the self-care element of the *NHS Improvement Plan* (Department of Health 2004b).

This briefing describes the NSF quality requirements and their implications for occupational therapy staff working with children and young people. In the NSF each quality requirement has a section describing evidence-based markers of good practice. Some of these are included here.



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## 2 Quality requirement 1: A person centred service

'People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves'. (Department of Health 2005a p19)

The aims of this standard are to offer holistic, integrated, interdisciplinary assessment and planning of a person's health and social care needs. An integrated system will prevent unnecessary repetition of basic information. Integrated multi-disciplinary teams, which include occupational therapists, are to have the appropriate training, skills and expertise to provide coordinated care.

Assessment and care planning are ongoing processes, dictated by the changing needs of the person and their family and carers. Regular monitoring and review is needed to ensure that:

- Parents know how to access services through self-referral if their child's needs change. This may be through a practitioner with a special interest or another named contact.
- No equipment or service is withdrawn before a thorough reassessment of needs has been undertaken.
- There is continuity of health and social care services when needs change or children and young people move between services e.g. between children's and adult services, when they move home to live in another area, or when they move from hospital to home.

Services must be flexible enough to allow for both planned and unplanned reviews when a person's condition suddenly deteriorates or circumstances change.

The NSF recognises that detailed planning for young people with conditions such as cerebral palsy and muscular dystrophy needs to be carefully handled and that a great deal of support may be needed whilst transferring to adult services.

Parents and young people should have access to all the information, advice, education and support they need in order to manage their own care, if that is their choice. The NSF recommends that the Expert Patient programme is expanded to include children, young people and their parents. The programme, which should be available through all Primary Care Trusts (PCTs) by 2008, is part of supporting self-care and aims to improve quality of life by developing confidence and motivation so that people use their own skills and knowledge to take effective control of their condition. It is one of the key points in the *NHS Improvement Plan* (Department of Health 2004b) and *Supporting People with Long Term Conditions – an NHS and Social Care Model to Support Local Innovation and Integration* (Department of Health 2005b).

To support self-care, occupational therapists must provide information and advice, ensure young people and their parents have the skills and knowledge they need to manage their condition and, when appropriate, be a trusted and consistent person for contact.

Occupational therapists will be members of multi-disciplinary and multi-agency teams and will undertake assessments of health, social, emotional, cultural and occupational needs, care planning and review.

Staff at all levels should have training to ensure that they give information and advice effectively and sensitively, taking into account the language and cultural needs of people from black and minority ethnic groups and the needs of people with sensory and cognitive impairments.



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**Markers of good practice** include timely assessment of current and anticipated needs resulting in an individual care plan that is regularly reviewed; a named person who is a point of contact for information and advice; and transition planning for all life changes.

### **3 Quality requirement 2: Early recognition, prompt diagnosis and treatment**

'People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible'.  
(Department of Health 2005a, p24)

Occupational therapists may be involved in the early recognition, diagnosis and treatment of people with neurological conditions. Early diagnosis can reduce stress and anxiety for parents. Providing information and advice in the early stages of illness can make a difference to the way families cope with situations. Specialist practitioners should be available to offer timely access to therapy and support, if necessary before the diagnosis is confirmed.

Occupational therapists may be involved in assessing the need for assistive technology to support children or young people with rapidly progressing conditions. Protocols are required that allow for referrals, assessment and provision to be fast-tracked where necessary.

### **4 Quality requirement 4: Early and specialist rehabilitation**

'People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support'.  
(Department of Health 2005a, p31)

Within hospitals or other specialist settings occupational therapists are part of inter-disciplinary teams of expert professionals who deliver planned, goal-oriented rehabilitation. They will be delivering therapy to develop skills in daily living, play and other appropriate activities as well as the assessment for, and provision of, equipment.

Occupational therapists will need strong links with other services such as, housing, social services, wheelchair services, community equipment services, education and so on, in order to plan a coordinated, seamless transition of care when the child or young person is ready to go home. They may also be involved, as part of a multi-disciplinary team, in the assessment and provision of highly specialised equipment for environmental control, mobility and communication.

### **5 Quality requirement 5: Community rehabilitation and support**

'People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them live as they wish'.  
(Department of Health 2005a, p35).



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Occupational therapists working with children and young people provide advice, support and rehabilitation. They are required to have the knowledge and skills that are needed to offer high quality interventions, part of which will be to guide and educate parents and carers to deliver rehabilitation as part of their everyday life.

**Markers of good practice** include:

- the provision of local rehabilitation services that offer specialist expertise;
- health and social services working together; and
- rehabilitation programmes that are based on individual goals and promote participation in everyday life.

## **6 Quality requirement 6: Vocational rehabilitation**

'People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities'.

(Department of Health 2005a, p39)

Occupational therapists help young people to develop life skills in preparation for independent living, work and/or continuing education. They may be involved in providing information, advice, assessments, or other occupation based interventions as well as practical support in the workplace, training or educational establishment.

## **7 Quality requirement 7: Providing equipment and adaptations**

'People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life'.

(Department of Health 2005a, p43)

Occupational therapists have a principal role in the assessment and provision of assistive technology and minor and major adaptations and in giving information and advice.

Three main categories of equipment are mentioned:

- Equipment to help with activities of daily living, sensory impairment and mobility.
- Specialist, custom-made equipment such as environmental controls and computer equipment.
- Equipment to prevent deterioration (such as contractures and hip dysplasia).

Assessment and provision is often specialised and services should be coordinated to be effective. Equipment needs should be included in the integrated care plan (quality requirement 1) with regular reviews. Some equipment may need to be provided on trial to ensure that it is suitable and parents and carers must be trained in its use. They may also need ongoing practice and support especially when new equipment is first provided. Further information about assessment and provision of equipment and minor adaptations can be found at [www.icesdoh.org](http://www.icesdoh.org) (accessed 29/03/2006).



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Services providing assistive technology and adaptations need to anticipate change and respond rapidly if necessary, especially for those people with rapidly deteriorating conditions. Duplication of assessments should be avoided by using integrated occupational therapy services, joint assessments by health and social care staff and the use of the single assessment process or the common assessment framework (Department for Education and Skills 2005) for children and young people.

Occupational therapists have a major role in the assessment and provision of suitably adapted housing. Following assessment, minor adaptations, such as stair rails, handrails, grab rails and simple ramps, are usually provided through the local community equipment service. Close working arrangements will be needed with local authority housing departments for major adaptations.

*Minor adaptations without delay* provides guidance and is available on the College of Occupational Therapists website [www.cot.org.uk](http://www.cot.org.uk) (accessed 29/03/2006).

Fast-track arrangements for the assessment and provision of assistive technology may be required for children and young people with rapidly deteriorating conditions, (quality requirement 3).

**Markers of good practice** include:

- Assistive technology/equipment needs are documented in the integrated care plan.
- Access to integrated community equipment services and specialist assistive technology services which offer specialist assessments; advice and support in using direct payments for equipment and vouchers for wheelchairs; equipment on temporary loan or trial; and regular ongoing reviews.
- Specific arrangements are in place to fund specialised equipment such as communication devices, electric standing supports and specialist seating.
- Close working arrangements are developed between social services and housing departments to ensure the timely provision of suitably adapted housing and purpose-built accommodation.
- Adaptations are provided in line with the good practice guide: *Delivering Housing Adaptations for Disabled People* (Office of the Deputy Prime Minister 2004), available on [www.odpm.gov.uk/index.asp?id=1152864](http://www.odpm.gov.uk/index.asp?id=1152864) (accessed 29/03/2006).

## **8 Quality requirement 8: Providing personal care and support**

'Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home' (Department of Health 2005a p47).

Direct Payments can give people more choice and control over the services they receive. The *Health and Social Care Act 2001* places a duty on local authorities to make Direct Payments available to people who want them, including parents of disabled children and disabled children aged 16 or over, in their own right. Direct Payments cannot be used for identified health needs, even when this is part of a joint care package. They can only be used for social care provision.

For more information go to:

[http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/DirectPaymentsArticle/fs/en?CONTENT\\_ID=4104420&chk=GQsPsD](http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/DirectPaymentsArticle/fs/en?CONTENT_ID=4104420&chk=GQsPsD) (accessed 29/03/2006).



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Successful care at home includes the provision of rehabilitation and support from a range of services including occupational therapy.

### 8.1 Assessment of need for community care services

*Fair Access to Care Services (FACS)* guidance (Department of Health 2003a) provides a framework for determining eligibility for adult care services. The guidance is not prescriptive, so individual services may differ depending on their resources. The FACS guidance does not apply to children. However, the general principles of setting criteria and determining eligibility does apply to children because these principles originate not with the FACS guidance but in the decision of the House of Lords in the case of *R v Gloucestershire CC, ex p Barry*. In this case the provision of services and equipment for adults under section two of the *Chronically Sick and Disabled Persons Act 1970* applied to both children and adults. The principles underlying the Gloucestershire decision were that once an eligible need for services has been assessed then the local authority has a duty to meet that need within a reasonable period of time. It can therefore be taken to apply to children. For information go to:

<http://www.icesdoh.org/article.asp?Topic=144#2> (accessed 29/03/2006).

When a need is identified within the local eligibility criteria, there is a duty to meet that need. If the solution to a need is the provision of equipment, service providers have the responsibility to provide it. For the full guidance go to:

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/FairAccessToCare/fs/en> (accessed 29/03/2006).

### 8.2 Assessment of need for fully funded NHS continuing care

Assessments of need should take into account the complex needs of children and young people with long-term conditions. They may have needs for daily personal care, mobility, management of spasticity, seizures, tissue viability, continence or medication, need for help with communication, breathing or cognition, and emotional or behavioural difficulties. These needs will vary in their complexity, intensity and unpredictability.

Occupational therapists will contribute to assessments for continuing care and will carry out assessments to identify social care needs.

Reassessment should be carried out promptly for both NHS continuing care and social care when needs change. For children and young people with rapidly deteriorating conditions it will be necessary to draw up specific plans at an early stage.

**Markers of good practice** include:

- appropriate training for therapy staff in the management of long term conditions, specifically neurological conditions;
- equitable access to assessments and services for people with long term conditions based on their needs;
- support to use direct payments; and
- assessments that take account of social inclusion, independent living and preventative care.

## 9 Quality requirement 9: Palliative care

'People in the later stages of long term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and



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meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care'. (Department of Health 2005a, p 51)

Children and young people are not specifically mentioned here but recently published guidance on commissioning palliative care for children and young people reiterates this requirement (Department of Health and Department for Education and Skills 2005a).

## 10 Quality requirement 10: Supporting family and carers

'Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carers and in their own right'. (Department of Health 2005a, p 55)

Under the *Carers (Equal Opportunities) Act 2004*, local councils have a duty to inform carers of their right to an assessment of their own needs, including their wishes to work, or participate in leisure or training opportunities. Services must be able to respond properly to urgent requests for help.

**Markers of good practice** which occupational therapists should include in their interventions are that carers:

- can choose the extent of their caring role;
- are treated as partners in care;
- are offered an integrated health and social care assessment;
- have appropriate training, including moving and handling and how to use any equipment provided;
- have a written care plan and regular reviews;
- have an allocated contact person; and
- are given the opportunity to work in partnership with specialist teams.

## 11 Quality requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings

'People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting'. (Department of Health 2005a, p59)

Whilst acquired brain injury and spinal cord injury are mentioned specifically in quality requirement 11, muscular dystrophy, cerebral palsy and other conditions such as spinal muscular atrophy are not. However the principle remains the same, that specific needs relating to the long-term condition must be identified and met.

Quality requirement 1 states the need for an integrated care plan and this plan must be continued, as far as possible, during a hospital admission or admission into respite care. This plan may include specific information about medication, bladder and bowel management, the use of specialist equipment and details about personal care, functional needs and therapy programmes. Occupational therapists contributing to this plan should ensure that it is followed during a hospital admission or during respite care. Training for hospital or care staff in the correct use of equipment may be necessary. Occupational therapists are often involved in this training and in providing information and support to hospital and care staff in order for them to



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develop a better understanding of the needs of children and young people with long-term conditions.

**Markers of good practice** include:

- Ensuring the integrated care plan is available to all relevant staff.
- Identifying special needs, including such things as personal care programmes and special equipment, for planned admissions.
- Having protocols in place for emergency admissions so there can be contact with the local care team and any specialist teams and ensuring there is evidence of consultation with these teams and with the family.

## 12 Additional information

This section briefly describes additional relevant information.

### 12.1 Managed local networks

The NSF for long term conditions recommends that staff, including occupational therapists, working in specialist centres who have specialist skills, provide training and information to support staff working in the community, or in other hospital departments. The NSF advocates the development of managed neuroscience clinical networks in order to share skills, information and knowledge. These networks should work across traditional service and professional boundaries.

Managed local networks are 'linked groups of health professionals and organisations from primary, secondary and tertiary care, and social services and other services working together in a coordinated manner'

(Department of Health and Department for Education and Skills 2005b, p8)

Their principal aim is to ensure that all agencies responsible for delivering care work together. The focus should be agreed by participants and may be based on a geographical area, on a specific service or specific group of service users, or on commissioning or clinical groups.

A toolkit is available to help people understand the advantages of working and planning services in this way and can be found at:

[www.dh.gov.uk/assetRoot/04/11/43/68/04114368.pdf](http://www.dh.gov.uk/assetRoot/04/11/43/68/04114368.pdf) (accessed 29/03/2006).

### 12.2 National service framework for long term conditions – good practice guide

This guide has been developed by the Department of Health (2005c) for anyone involved in the planning, commissioning and implementation of the NSF. It includes sections on:

- getting stakeholders involved;
- inter-agency collaboration;
- service models;
- self-assessment tool for organisations;
- care coordination; and
- information needs and provision.

The full guide can be downloaded from:

[www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/fs/en](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LongTermConditions/BestPractice/fs/en) (accessed 29/03/2006).



### 12.3 The contribution of allied health professionals (AHPs)

Three initiatives highlight the contribution that allied health professionals can make to the delivery of the NSF for long term conditions. These are:

- *Meeting the challenge: A strategy for the allied health professions* (Department of Health 2000) looks at how AHP roles can be developed and supported and the central role they have to play in delivering the *NHS Improvement Plan* (Department of Health 2004b). For the full report go to: [www.dh.gov.uk/assetRoot/04/05/51/80/04055180.pdf](http://www.dh.gov.uk/assetRoot/04/05/51/80/04055180.pdf) (accessed 29/03/2006).
- *10 Key Roles for AHPs* (Department of Health 2003b) is described in: [www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4047393&chk=tfbxA](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4047393&chk=tfbxA) (accessed 29/03/2006).
- *The national and primary care trust (NatPaCT) self assessment tool for AHPs* (NHS Modernisation Agency 2003), which describes significant issues for the delivery, modernisation and commissioning of AHP services. For the full document go to: [www.natpact.nhs.uk/uploads/aph\\_framework.pdf](http://www.natpact.nhs.uk/uploads/aph_framework.pdf) (accessed 29/03/2006).

### 12.4 Supporting people with long term conditions

The policy document *Supporting People with Long Term Conditions – An NHS and Social Care Model to support local innovation and integration* (Department of Health 2005b) has a strong emphasis on primary care. It advocates the development of multi-disciplinary teams working across health and social care partnerships and self-care as described in the *NHS Improvement Plan* (Department of Health 2004b). The self-care model includes:

- *self-care;*
- *case management; and*
- *disease management.*

The *Expert patient programme* (Department of Health 2001) is part of the strategy for self-care and is described briefly in quality requirement 1. The full report can be downloaded from [www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf](http://www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf) (accessed 29/03/2006).

Some children and young people with long-term conditions may benefit from a case management approach to their care. This is designed to identify the most vulnerable people (based on co-morbidity, the number of medicines taken, the number contacts with their GP, or other high risk factors) and those with highly complex long-term conditions. The case management approach coordinates health and social care and ensures that services work together. Case managers are now beginning to be employed to work specifically with children and young people.

Some young people with long-term conditions might also benefit from a disease specific care management approach in order to slow down disease progression and reduce disability. This has been shown to be effective in the management of asthma and diabetes. Confusingly this is sometimes also known as case management.

### 12.5 Local strategic partnerships and local area agreements

People with long-term conditions have needs that are met by services other than those provided by health and social services. *Local Strategic Partnerships and Local Area Agreements* (Office of the Deputy Prime Minister 2005) provide a strategic framework through which these services are coordinated and delivered.



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Although not statutory, Local Strategic Partnerships (LSPs) exist in almost all parts of the country bring together local authorities, service providers and the private, voluntary and community sectors. LSPs aim to coordinate local service provision better and support the delivery of the NSFs. Information about LSPs can be obtained on a regional basis from individual government offices or from the Office of the Deputy Prime Minister (ODPM) website [www.odpm.gov.uk](http://www.odpm.gov.uk) (accessed 29/03/2006).

Working through Local Strategic Partnerships, Local Area Agreements (LAAs) are being piloted in 21 areas. Local Area Agreements are based on agreements between government, local authorities and local partners, including PCTs and Children's Trusts, about the local delivery of national targets. They reinforce joint working between partners and bring together different funding streams. A key component of the local area agreement is the *Children and Young People's Plan*, which is described in *Every Child Matters: Change for Children* (Department for Education and Skills 2003).

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