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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Cerebral Palsy: diagnosis and management in children and young people

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Checking for updates and scope: before scope consultation (to be completed by the Developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they?

Please see other signed form before consultation of the draft scope.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

Please see other signed form before consultation of the draft scope.

Completed by Developer Vanessa Delgado Nunes

Date 25 June 2014

Approved by NICE quality assurance lead _____

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Date _____

2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Please see other signed form after consultation of the draft scope.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

Please see other signed form after consultation of the draft scope.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'information for the public' recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss
- British Sign Language videos for a population deaf from birth
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

Please see other signed form after consultation of the draft scope.

Updated by Developer Vanessa Delgado Nunes

Date 15th October 2014

Approved by NICE quality assurance lead _____

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Date _____

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3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

We have covered the potential equality issues in the review protocols and the description of linking evidence to recommendations.

The following recommendations are examples of how the equality issues identified during scoping have been addressed by the Committee.

Functional or cognitive disabilities

Information and support

Ensure that information and support focuses as much on the functional abilities of the child or young person with cerebral palsy as on any functional impairment.

Information about prognosis

Be aware of the following in relation to prognosis for speech development in a child with cerebral palsy, and discuss this with parents and carers as appropriate:

- Around 1 in 2 children with cerebral palsy have some difficulty with elements of communication (see recommendation 1.9.1).
- Around 1 in 3 children with cerebral palsy have specific difficulties with speech and language/ talking.
- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of difficulties with speech and language.
- Uncontrolled epilepsy may be associated with difficulties with all forms of communication including speech.
- A child with bilateral spastic, dyskinetic or ataxic cerebral palsy is more likely to have difficulties with speech and language than a child with unilateral spastic cerebral palsy.

Causes of pain, discomfort and distress

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3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Explain that many children and young people with cerebral palsy experience discomfort or pain for a variety of reasons, and that this is more common in those with more severe motor impairment.

Social care needs

Address and review the specific needs of the child or young person with cerebral palsy in relation to accessing their physical environment (for example home, school, healthcare, workplace, community), in order to optimise their functional participation.

Think about the following aspects:

- mobility
- equipment, particularly wheelchairs and hoists
- transport
- toileting and changing facilities.

Communication difficulties

The following recommendations have been selected as examples of how the Committee considered communication difficulties whilst developing the recommendations:

Speech, language and communication

Offer interventions to improve speech intelligibility, for example targeting posture, breath control, voice production and rate of speech, to children and young people with cerebral palsy:

- who have a motor speech disorder and some intelligible speech and
- for whom speech is the primary means of communication and
- who can engage with the intervention.

Refer the child or young person if there are ongoing problems in using augmentative or alternative communication systems to a specialist service in order to tailor interventions to their individual needs, taking account of their cognitive, linguistic,

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3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

motor, hearing and visual abilities

Regularly review children and young people who are using augmentative or alternative communication systems, to monitor their progress and ensure that interventions continue to be appropriate for their needs.

Provide individualised training in communication techniques for families, carers, school staff and other people involved in the care of a child or young person with cerebral palsy.

Causes of pain, discomfort and distress

When assessing pain in children and young people with cerebral palsy:

- recognise that assessing the presence and degree of pain can be challenging, especially if there are communication difficulties or learning disabilities
- ask about signs of distress and sleep disturbance at every contact
- recognise that pain-related behaviour can present differently compared with that in the wider population.

Age appropriate

The following recommendations have been selected as examples of how the Committee considered age whilst developing the recommendations:

Information and support

Ensure that the child or young person and their parents and carers are given personalised information from a specialist about the following topics as appropriate:

- menstruation
- fertility
- contraception

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3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

- sex
- sexuality
- parenting.

Ensure that professionals involved in providing future care for young people with cerebral palsy have sufficient training in order to address all their health and social care needs.

Transition

Recognise that challenges for young people with cerebral palsy continue into adulthood, and ensure that their individual developmental, social and health needs, particularly those relating to learning and communication, are addressed when planning and delivering transition.

Ensure that professionals involved in providing future care for young people with cerebral palsy have sufficient training in order to address all their health and social care needs.

1.6 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

English not being first language

Take into account that English may not be the first language of children and young people with cerebral palsy or their parents or carers. Provide an interpreter if necessary. Follow the principles in the NICE guideline on [patient experience in adult NHS services](#).

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1.6 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Religion or belief

When assessing care needs, take into account the role of any social, cultural, spiritual or religious networks that support the child or young person with cerebral palsy and their family.

1.7 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

We have covered considerations of equality issues in the review protocols and the description of linking evidence to recommendations. Please refer to the following Linking Evidence to Recommendations sections in the full guideline as examples of where some of the guideline's equality issues have been described alongside the Committee's deliberations and justifications to the recommendations:

Section 28.5 on social care needs

Section 11.5 on information and support

Section 29.5 on transition

Section 10.6 on prognosis of walking, talking and life expectancy.

Sections 24.5 on assessment of mental health problems and 25.5 on management of mental health problems.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

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No.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

Some examples of recommendations that that can alleviate barriers to access to services in the guideline are:

Ensure that the child or young person has access to a multidisciplinary team that:

- is able to meet their individual needs
- can provide the following expertise, through a local network of care
 - paediatric medicine
 - adult medicine (if appropriate)

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3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

- nursing care
- physiotherapy and occupational therapy
- speech and language therapy
- dietetics
- psychology
- social care.

Ensure that routes to accessing specialist teams involved in managing comorbidities associated with cerebral palsy are clearly defined on a regional basis.

Completed by Developer Vanessa Delgado Nunes

Date 30th June 2016

Approved by NICE quality assurance lead



Date

20/7/16.