NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

EQUALITY IMPACT ASSESSMENT

NICE has a duty to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations between particular population groups. The purpose of this form is to document the consideration of equality issues at each stage of the guideline development process. This equality impact assessment is designed to support NICE's compliance with the Equality Act 2010 and the Human Rights Act 1998, and to provide the Guidance Executive of NICE with assurance of compliance.

The table below lists the characteristics and other equality factors NICE needs to consider. It covers not just population groups sharing the 'protected characteristics' defined in the Equality Act but also those affected by health inequalities and inequities in access to health, public health and care services associated with socioeconomic factors and with other forms of disadvantage. Although listed separately, these categories often overlap.

The form is used to:

- record equality issues raised in connection with the guideline by anybody involved
- demonstrate that these issues have been given due consideration by explaining what impact they have had on the guideline's recommendations, or why there was no impact
- give assurance that the recommendations will not discriminate against any equality group
- highlight recommendations aimed at advancing equality of opportunity or fostering good relations.

The equality impact assessment should be completed by the Developer and Committee Chair. NICE quality assurance staff must sign off the completed equality impact assessment before the form is published on NICE's website.

Protected characteristics

- Age
- Disability
- Gender reassignment
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

Note:

- The characteristic of marriage and civil partnership is protected only from unlawful discrimination. There is no legal requirement to consider the need to advance equality and foster good relations.
- 2) The definition of direct discrimination covers less favourable treatment of someone associated with a person with a protected characteristic, such as the carer of a disabled person.

Socioeconomic factors

The relevance and nature of socioeconomic factors will vary according to the guideline topic. They may include deprivation and disadvantage associated with particular geographical areas or other geographical distinctions (for example, urban versus rural).

Other definable characteristics

Certain groups in the population experience poor health because of circumstances distinct from – though often affected by – sharing a protected characteristic or socioeconomic factors. The defining characteristics of groups of this sort will emerge from the evidence (although, on occasions, a guideline topic will explicitly cover such a group). Examples of groups identified in recent NICE guidelines are:

- refugees
- asylum seekers
- migrant workers
- looked-after children
- people who are homeless
- prisoners and young offenders.

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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.

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

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

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

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:

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

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, 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.

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

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
- 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 <u>patient experience in adult NHS services</u>.

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.

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

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?

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)
 - 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: Sarah Willett

Date: 20 July 2016