

NICE Clinical Guideline: Cerebral Palsy in Adults Over the Age of 25 Years

Stakeholder scoping workshop notes

9th November 2016

Notes from the workshop

General comments

The stakeholders suggested that the recent implementation of the Education Healthcare Plans (introduced across England and Wales during 2014) proposes that young people can be educated up to 25 years. Stakeholders noted that this would mean that adults with cerebral palsy might have access to some services for social care up to this age rather than up to age 18 only. Therefore it is appropriate that the topic of access to services should be covered in the scope of the guideline for people with cerebral palsy beyond age 25 years.

Stakeholders agreed that the key area of 'interventions that promote function and impact on participation' is very important and highlighted that people with cerebral palsy often value interventions that improve participation more than interventions that help to improve physical outcomes only.

The stakeholders raised that independent mobility interventions that promote social inclusivity and participation in activities would be important to consider within the scope.

There was a difference of opinion amongst stakeholders about age groups within the guideline. Some thought that a division of age groups along the lines of younger and older adults may be helpful for the whole guideline and should include in some instances 18 to 25 year old young adults. This age group would be an important subgroup because it is the time when young adults have to develop independent living skills due to the transition from full-time education into other services. Other stakeholders disagreed because these skills are important throughout adulthood and noted that the guideline should start at age 25 to avoid confusing overlap with the children's guideline.

Some stakeholders mentioned the importance of including leisure and hobbies due to the impact on emotional wellbeing. The inclusion of visual impairments was suggested by another stakeholder.

Scope title

Some stakeholders raised concerns that the title of the guideline does not reflect that the sub-population of adults (over the age of 18) will be addressed in the key area of spasticity.

Groups that will be covered

Stakeholders commented that cerebral palsy in adults is multifaceted. There are people who are more able and are coping in society; then there are those who are struggling, who are

perhaps older, have no family support, or are more severely disabled. These were raised as possible equalities issues.

Stakeholders agreed that subgroups should not only include adults with spasticity but also other associated movement disorders.

Groups that will not be covered

Stakeholders raised that there was a confusion in the draft scope between groups that will not be covered and a section called areas that will not be covered. The latter included learning disabilities and concerns were raised about this as a potential exclusion.

Key areas that will be covered

Stakeholders agreed that the draft scope covered the main topics that need to be addressed in adults with cerebral palsy.

The stakeholders made suggestions for possible additions to topics:

- access to services including leisure and exercise
- aqua therapy
- sport and leisure activities (for example wheelchair basketball, bowling etc)
- electronic assistive technologies.

The stakeholders made the following suggestions with regard to service configuration.

- Stakeholders agreed that there currently are only specialist cerebral palsy services for children but not for adults and that it is important to review the evidence for the effectiveness of such services in adults.
- Stakeholders also agreed that there is currently a large variation in access to services (for example screening services but also other primary or secondary care services).

Key areas that will not be covered

Stakeholders raised concerns about the exclusion of learning difficulties in this section. If mentioned in this section, stakeholders agreed that this should be restricted to the management of learning disabilities since this is covered in an already existing guideline.

Equalities

Stakeholders raised the following possible equalities issues:

- people with no social support
- people who have uncontrolled epilepsy
- families with several people who have disabilities due to genetic factors (Asian families were mentioned here).

Care settings

No issues were raised.

Draft review questions

Discussion took place on the draft review questions and stakeholders made the following suggestions.

Q 1.1 – It was queried whether management of abnormal muscle tone would also address pain.

Q 1.3 – With regard to the management of dystonia it was noted that tetrabenzin and trihexaphenadol are the most commonly used anticholinergics. It was also highlighted that the evidence for this topic may be limited.

Q 2.1 – Stakeholders suggested that vaccinations could be considered a prophylactic treatment. They also noted that surveillance of respiratory health should include the use of sleep studies. Stakeholders also highlighted that chest clearance techniques or chest management were better terms than chest physiotherapy.

Q2.3 – Stakeholders commented that osteopenia could be included as this could be identified by the same imaging techniques. The issue of access to imaging was raised since this may include sedation or anaesthesia to enable this to happen for adults with cerebral palsy and spasticity.

Q2.4 – It was suggested that this question could be removed or combined with Q3.2 and that there was some repetition or overlap in review questions in section 2 and those in section 3.

Q3.2 – Stakeholders agreed that orthopaedic surgery could be removed from this review as it will be covered in Q3.3. It was noted that there are specific activities or interventions that are used to improve balance and that they could be included in this question.

Q3.3 – Stakeholders noted the overlap between Q3.2 and Q3.3.

Q 3.4 – Stakeholders raised concerns that currently this question was too narrow and needed to include further detail of treatments that would be considered by physiotherapists in current practice. It was also noted that the wording needed to be revised from 'improve function' to 'maintain function'.

Q3.5 – A stakeholder suggested that this question would be clearer if it read: 'How can the communication needs of adults with cerebral palsy best be met to facilitate participation?'.

Q4.1 – The issue of pain was considered to be important by all stakeholders. Further causes of musculoskeletal pain were highlighted, for example pain caused by repetitive strain injuries, or pain related to spinal deformity as well as joint pain, pain related to muscle fatigue and soft tissue pain (muscle cramps).

Q5.1 – Service delivery was considered to be an important topic by all stakeholders. It was suggested that this should be divided into:

- necessary components of a network of care
- barriers to access to care.

Outcomes

Outcomes were discussed and it was suggested that the following could be included or changed:

- hospital admissions could be changed to unplanned hospital admissions
- health-related quality of life should not only be related to the person with cerebral palsy but also their family members or carers
- falls or risk of falls could be added
- communication could be added to participation.

Guideline Committee composition

Stakeholders made the following suggestions about the proposed composition of the Committee:

- a geriatrician may not be needed as a full member
 - a pharmacist could be a full member
 - a psychologist could be a co-opted rather than a full member
 - there could be some representation from social care
 - a dietitian could be a co-opted member
 - a neurologist ought to be included (perhaps a neuro-rehabilitation specialist).
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