National Institute for Health and Clinical Excellence

Spasticity in Children

Stakeholder Comments – Draft scope

Please enter the name of your registered stakeholder organisation below.

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Stakeholder organisation:	**BSRM**
Name of commentator:	**Margaret Phillips on behalf of the Executive Committee**

Comment No.	**Section number** Indicate **number** or **'general'** if your comment relates to the whole document	**Comments** Please insert each new comment in a new row. Please do not paste other tables into this table, as your comments could get lost – type directly into this table
Example	3.4.6	Our comments are as follows ……….
Proformas that are not correctly submitted as detailed in the line above may be returned to you		
1	3.1.l	Uncorrected deformities may also cause difficulties in caring of themselves, not just due to pain, impaired function and reduced mobility. It may be more accurate to include caring amongst this list, rather than them being a cause of difficult care. We would also suggest it is 'uncorrected deformities and spasticity' as spasticity of itself may cause these problems, even without the deformity. We would suggest adding lying and seating and further notable problems.
2	3.1.m	Difficulties also in development of social and educational roles and growing independence expected in paediatric development, thus reducing educational and societal opportunities. This (and employment opportunities) could be considered as a separate paragraph. The distinction in category between 3.1l and m is not clear. ICF terminology could be used to assist in this distinction if the working party is familiar with it and if thought that the audience would also be familiar with it. Otherwise, one system would be to have one paragraph about mobility, seating and functional activities, one about caring, one about participatory issues (socialisation, education and employment), and one about pain and secondary deformity.

3	3.2.d	Aids and appliances are also used and issued, other than just orthotics. Specialised seating and posture management is the remit of various disciplines (varies regionally and within services) and is a key aspect of management in many – (may be physiotherapy, occupational therapy or clinical bioengineer led- in some areas seating is managed by regional disablement services). It may also be useful to refer to use of orthotics rather than 'bracing' as this is only one aspect of what orthoses are designed to do. There are several related issues concerned with orthoses that affect their use, such as their comfort and cosmesis.
4	3.2.e	This addresses pharmacological and surgical issues and not general well health advice to reduce those aspects of impairment or disease or lifestyle which may precipitate or aggravate spasticity. Advice on general issues such as posture, skin integrity, pain management, constipation management etc is also of value. This could go as a preliminary point at the start of section 3.2.
5	3.2e	Botulinum toxin B could also be included.
6	3.2.e	There is significant evidence of the usefulness of botulinum toxin in spasticity management including in Cerebral Palsy. Many clinical indications remain unlicensed and it is hardly practicable to expect pharmacological industries to gather data for these licences at this stage. Routine practice has moved on beyond this.
7	3, final paragraph	Could also include refilling and cover rota for baclofen pumps as an issue where provision is limited.
8	4.1.1	Orthopaedic surgeons may well indicate that skeletal maturity is not yet fully reached at 19 years.
9	4.3, introductory paragraph	A first point about consideration of the issues raised in our point 4 could be included here.
10	4.3.1.a	Also occupational therapy.
	4.3.1a	This, or a separate point here, or 4.2 (healthcare setting), would also be an appropriate place to consider a multidisciplinary approach to spasticity in children.
11	4.3.1.b	Also specialised seating, sleep systems and posture management. Also other aids and appliances.
12	4.3.1.c	Also cannabinoids and gabapentin.
13	4.3.1d	Also botulinum toxin type B.
14	4.3.1f	Also to improve posture and care needs.
15	4.3.1	There is no reference to appropriate interface with transition services to adulthood nor to vocational/occupational entry for persons with disability. This could be with regard to timing, mechanism and types of service. We would suggest that transition, and responsibilities and provision for continued interventions such as baclofen pump refilling are addressed at an early stage.
16	4.3.1 and 3.2e	Functional electrical stimulation may have an effect on spasticity, as well as function, in children, and there is a literature concerning this area. Perhaps it could be considered as another modality to address.
17	4.4	If the outcomes are meant to be hierarchical I would suggest that improvement of function and an addition of improvement in care (for those very disabled young people where optimised care is going to be the main route to a good quality of life) should come above improvement in spasticity. You might also consider a caveat with the reduction in spasticity statement as it only being of use if it improves some measure of pain, function, quality of life or care.

18	4.4.e	Acceptability and tolerability in children and young people: this should refer both to tolerability of treatment and aids/orthotics etc provided and to acceptability and tolerability of the level of impairment, activity and participation experienced by the child and carers by the disease process, its natural history, the treatment incurred and the consequences of lack of treatment. Transition might also be considered here, in that the mode of giving botulinum toxin and use of orthoses in childhood can significantly affect a child's acceptance of these forms of treatment in adulthood – for instance we have had problems in adult services with young people having been put off botulinum toxin by the associated use of a GA or midazolam.

Please add extra rows as needed

Please email this form to: Spasticity@nice.org.uk

Closing date: 5pm on 9 April 2010

PLEASE NOTE: The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion or the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.