

**Children and young people with disabilities and severe complex needs:  
integrated health and social care support**

Consultation on draft scope – deadline for comments by 5pm on Tuesday 5 February 2019  
email: [CYPseverecomplexneeds@nice.org.uk](mailto:CYPseverecomplexneeds@nice.org.uk)

	<p>Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline.</p> <p>In addition to your comments below, we would like to hear your views on these questions:</p> <ol style="list-style-type: none"> <li>1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?</li> <li>2. Which, if any, of the proposed review questions should consider barriers to care?</li> <li>3. For which questions would views and experiences of service users be most important to consider?</li> <li>4. What in your opinion are the most important and least important of the proposed review questions?</li> <li>5. Would you support the following alternative title for the guideline: "Disabilities and severe complex needs in under 25s: integrated health and social care support and service delivery and organisation?"</li> </ol> <p><a href="#">Developing NICE guidance: how to get involved</a> has a list of possible areas for comment on the draft scope.</p>
<p><b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):</p>	<p><b>Together for Short Lives</b></p>

<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		<b>N/A</b>	
<b>Name of person completing form:</b>		<b>James Cooper, Public Affairs and Policy Manager</b>	
<b>Type</b>		[for office use only]	
<b>Comment No.</b>	<b>Page number</b>  or ' <b>general</b> ' for comments on the whole document	<b>Line number</b>  or ' <b>general</b> ' for comments on the whole document	<b>Comments</b>  Insert each comment in a new row.  Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because....
1	1	18	We ask that, throughout the scope, NICE specifies that it applies to infants in addition to children and young people. This would help to make the guideline consistent with NG61 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.
2	1	27	We ask that this list includes life-limiting and life-threatening conditions.
3	2	3	We ask that NICE specifies that this could include infants, children and young people who have degenerative conditions, who are likely to lose skills and will need to be regularly reassessed.

Please add extra rows as needed

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4	2	11-30	<p>We ask that this list includes an inability to access short breaks for respite because their local NHS clinical commissioning group and their local authority:</p> <ul style="list-style-type: none"> <li>do not jointly commission them</li> <li>disagree with each other about which of them is responsible for commissioning them; and/or</li> <li>do not recognise the need to commission specialist short breaks which meet disabled children's complex health needs and which are different to short breaks needed by those with less complex needs.</li> </ul> <p>We ask that it also includes an inability to choose how and where they receive care because (i) there is a limited range of care settings to choose from within their local area and/or (ii) they are not given the opportunity to discuss their preferences and record them in a plan.</p>
	3	17-29	<p>We ask that the following are added to this list:</p> <ul style="list-style-type: none"> <li>Children Act 1989</li> <li>Chronically Sick and Disabled Persons Act 1970</li> <li>NHS Long Term Plan (2019) NHS England</li> <li>Universal Personalised Care (2019) NHS England</li> <li>Short breaks for carers of disabled children (2011) Department for Education.</li> </ul>
	4	3-17	<p>We ask that this list includes voluntary sector children's palliative care provider organisations, including children's hospices.</p>
	6	7-18	<p>We ask that this list includes initiating conversations with children and families about personal budgets – as personal health budgets, integrated personalised commissioning and/or education, health and care (EHC) plan personal budgets.</p>
	6	25-28	<p>We ask that this list includes 'End of life care for infants, children and young people with life-limiting conditions: planning and management' (2016) NICE guideline NG61.</p>
	9	3	<p>We ask that the list includes a new question: 2.2 What strategies are effective in initiating conversations with children and families about personal budgets – as personal health budgets, integrated personalised commissioning and/or education, health and care (EHC) plan personal budgets?</p>

Please add extra rows as needed

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- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, do not include attachments such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments.

**Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

Please add extra rows as needed

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