

Consultation on draft guideline – deadline for comment 5pm on 14 September 2021

email: CYPseverecomplexneeds@nice.org.uk

Checklist for submitting comments

- Use this comments form and submit it as a **Word document (not a PDF)**.
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **document name, page number and line number** of the text each comment is about.
- Combine all comments from your organisation into 1 response form. **We cannot accept more than 1 response from each organisation.**
- **Do not** paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; **do not** cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- 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. You may resubmit the form without attachments, but it must be received by the deadline.
- **We do not accept comments submitted after the deadline stated for close of consultation.**

You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](#).

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.

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Please read the checklist above before submitting comments. We cannot accept forms that are not filled in correctly.

We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.

In addition to your comments below on our guideline documents, we would like to hear your views on these questions. **Please include your answers to these questions with your comments in the table below.**

1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.
2. Would implementation of any of the draft recommendations have significant cost implications?
3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)
4. The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.

See [Developing NICE guidance: how to get involved](#) for suggestions of general points to think about when commenting.

How well do the recommendations:

- cover the issues in the scope
- reflect what the evidence says
- take account of the choices and preference of people affected by the guideline, and their information and support needs
- consider the needs of different groups
- use wording that is clear, easy to follow, and respectful
- Are there any possible inconsistencies or disagreements about how the committee interpreted and applied

the evidence?

- **Tell us about any additional evidence that should inform the guideline.**
- Do the research recommendations cover the important gaps in the evidence?

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education

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Organisation name (if you are responding as an individual rather than a registered stakeholder please specify).	Special Educational Consortium
Disclosure (please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry).	N/A
Name of person completing form	Chris Rees

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Comment number	Document [e.g. guideline, evidence review A, B, C etc., methods, EIA]	Page number 'General' for comments on whole document	Line number 'General' for comments on whole document	Comments <ul style="list-style-type: none"> • Insert each comment in a new row. • Do not paste other tables into this table, because your comments could get lost – type directly into this table. • Include section or recommendation number in this column.
1	Guideline	7	1.1.17	Please replace with 'SENDIAS services provide information, advice and support to children, young people and their families and carers to help them understand how systems work, what provision should be available, based on their specific needs and how to access it, this can included advocacy where needed. You can find out more about them in their Minimum Standards https://councilfordisabledchildren.org.uk/resources/all-resources/filter/inclusion-send/minimum-standards-iass which are also available in Easy Read.'
2	Guidance	15		Add reference to the SENDIAS here and wherever IAS is mentioned
3	Guidance	5	1.1.2	Some CYP may not want to attend all meetings but still need opportunities to input. Wording could be changed to 'invite young people to attend and include other accessible opportunities for young people to input into all meetings where their views should be represented' – Simply inviting CYP to meetings may not be enough for those with complex needs to actually input – discussions and opportunities for input need to be accessible. Accessible options may include sending a short 'about me' presentation, sending photo diaries, only attending parts of the meeting.
4		7	1.1.15	Add that information should be accessible (as well as up-to-date). It is also important to find out what information families want, rather than give them materials on policies and processes that may be overwhelming
5		7	1.1.18	This recommendation is confusing and presupposes that services will not be able to meet family's needs. If inviting this conversation from families, clear parameters would need to be set and there should be a focus on getting to the root of what they want and why, exploring alternatives that can meet some of their needs, where it is not possible to meet their expectations within a service.
		7	1.1.19	Add reference to DfE SEND Code of Practice
6		9	1.1.23	This section should include other ways children and young people can be involved e.g. submitting a presentation/photo essay/video. It could also explain that children and young people not have to stay

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				for the whole meeting to input into it, and encourage professionals to help young people to think about who they would like to be with them in the meeting.
7		10	1.1.29	Do <i>all</i> actions/action logs need to be shared with CYP? There may be a tension between transparency and being required to show children write-ups and actions which included potentially upsetting material e.g. around safeguarding needs, family breakdown, foetal alcohol syndrome etc. There should also be a focus on adjustments to the range of ways in which such information can be communicated. This balance should be acknowledged.
8		12	1.1.37	Change ‘unable to formulate a view’ to ‘unable to communicate their views,’ because behaviour, play etc. <i>is</i> a form of communication, particularly for nonverbal CYP and those with complex needs.
9		17	1.3.1	Clarify that any parent/carer and any practitioner working with a child can request an EHC needs assessment
10		17	1.3.3	Move, ‘or whether they have a diagnosis at all’ out of brackets, as lack of diagnosis is a key barrier to accessing EHCPs due to misperception that a diagnosis is needed
		17	1.3.4	LAs should not explain the ‘possible outcomes’ to CYP and parent carers when assessing needs – outcomes should be led by the child or young person. The SEN Code of Practice says outcomes should be personal, not led by services. Outcomes and aspirations are not subject to appeal, so they do not need to be limited in this way.
		21	1.4.1	It’s good to see that children and young people should be encouraged to express their life goals – this should apply to <i>all</i> CYP. Wording could be changed to ‘encourage all children and young people, including those with severe complex needs, to express their life goals and ambitions.’ Outcomes should be led by the CYP, supported by professionals rather than “decided” by the professionals as this guideline makes it seem.
		21	1.4.3	Outcomes should be developed/established with CYP in initial conversations (in the same way as aspirations) and then made SMART by professionals. This guidance suggests professionals should be deciding the outcomes for the child – which would undermine existing good practice where outcomes are child-led.
		21	1.4.5	There is a greater risk of compromising ambitions if they are made to be ‘realistic’, and are not subject to appeal. Practitioners should not be encouraged to question and overrule aspirations they feel as unrealistic or too high – if this is talking only about SMART outcomes, that should be clearer in these recommendations. Otherwise, this may undermine existing good practice (there is evidence of lack of ambition in Outcomes for disabled children and young people).

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		21	1.4.6.	1.4.6 is unclear as outcomes should not be a description of support needs, or based on existing provision. Could change to ‘Outcomes should be personalised to each child or young person. Do not assume that all children and young people with a particular diagnosis will have similar outcomes or will need the same support’
		23	1.4.14	Include other ways of young people providing their views in EHCPs which are already being used by areas implementing good practice, such as drawings, photo collages, like/dislike lists etc.
		24	1.4.16	CYP should be guiding the development of their outcomes – not just asked to understand them at the end
		26	1.4.22	Add section covering the final review - EHCP outcomes agreed at the final review before leaving school and moving to college must be fit-for-purpose, age-appropriate, and support the development of an appropriate study programme
		48	1.15.11	Have young people and families been consulted as to what support they want from key workers? There is evidence that families want the role to be informal and family-facing, providing support, advice and signposting for the family (including siblings who may need signposting to sibling support/carers support groups), rather than being professional facing.
		49	1.15.12	This section should emphasise the need for smooth and supported transitions between keyworkers to minimise disruptions to young people.
		57	1.17.6	As well as consulting CYP and families about <i>needs</i> to inform commissioning, commissioners must also work with CYP and families to “identify the outcomes that matter to children or young people with SEN or disabilities to inform the planning and delivery of services and the monitoring of how well services has secured those outcomes.” (SEN Code of Practice 3.31). This recommendation should include a mention of commissioning based on strategic outcomes – this is good practice which is increasingly being adopted across the country when commissioning services for complex CYP already. Could the wording be changed to “consult children and young people and their parents and carers, to ensure services meet the needs of the local population and enable them to reach the outcomes that matter to them.”
		57	1.17.9	Change to “commission services based on the needs and preferences of children and young people, and the outcomes that matter to them”
		60	1.18	Joint commissioning frameworks should be outcomes-based: focused on achieving the strategic outcomes they want to achieve for young people with complex needs.

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	Guidance	General	1.2	All sections on multi-agency working should encourage a clear approach focusing on early identification and relevant support and high quality communication and coordination between different agencies.
	Guidance	General		Clearer focus across the whole document on all duties relating to the Equality Act when supporting children and young people - reasonable adjustments to support children who have SEND, supporting a safe and welcoming environment in all settings, with all practitioners and all planned approaches ensuring best access to relevant support.
	Guidance	General		Stronger sense of accountability on the need for professionals to work together to support children and young people. Added emphasis on oversight to ensure this happens effectively and consistently.
	Guidance	General		A longer-term focus on raising ambitions when developing Outcomes. From the earliest age there needs to be a focus on preparing for adulthood so that at every stage disabled children are better prepared for the next stage of their lives, with particular reference to decision making, communication and planning - https://www.sendgateway.org.uk/resources/preparing-adulthood-earliest-years-review-guide

Insert extra rows as needed

Data protection

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