

**Consultation on draft guideline – deadline for comments 5:00pm on Monday 20 November 2017 email: [LDCB@nice.org.uk](mailto:LDCB@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.</p> <p>We would like to hear your views on the draft recommendations presented in the short version and any comments you may have on the evidence presented in the full version. We would also welcome views on the Equality Impact Assessment.</p> <p>We would like to hear your views on these questions:</p> <ol style="list-style-type: none"> <li>1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.</li> <li>2. Would implementation of any of the draft recommendations have significant cost implications?</li> <li>3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)</li> </ol> <p>See section 3.9 of <a href="#">Developing NICE guidance: how to get involved</a> for suggestions of general points to think about when commenting.</p>		
<b>Organisation name – Stakeholder or respondent</b> (if you are responding as an individual rather than a registered stakeholder please leave blank):		National Network of Parent Carer Forums		
<b>Disclosure</b> Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		None		
<b>Name of commentator person completing form:</b>		Kay Moore		
<b>Type</b>		[office use only]		
<b>Comment number</b>	<b>Document</b> (full version,	<b>Page number</b> Or	<b>Line number</b> Or	<b>Comments</b>

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	short version or the appendices	'general' for comments on the whole document	'general' for comments on the whole document	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.
1	Short	7	11-17	<p>The NNPCF welcome the aims and principles of this guideline. As a parent led organisation we strongly believe that:</p> <p>Children, young people and families should be supported to have a good quality of life. They should be treated with respect and have an expectation of a home in their local community</p> <p>Children and young people should be kept safe but at the same time supported to take positive risks</p> <p>Children and young people should have choice and control over their lives</p> <p>Children and young people's support should be provided in the least restrictive way</p> <p>Children and young people should get equal health outcomes to the rest of the population.</p> <p>We fully recognise the unprecedented financial challenge that Local Areas (LAs/CCGs) are facing and the need to deliver cost-effective quality services when numbers and complexity of needs are rising.</p> <p>Families feel frustrated and lack confidence in the system.</p> <p>The NNPCF strongly believe that working with parents, carers, children and/young people is at the heart of legislation. There is a better way forward which is to treat parent carers and young people as equals and allow them to participate in decisions which affect them and in planning services.</p> <p>There are overlap with the SEND Reforms introduced by Children and Families Act 2014:</p> <ul style="list-style-type: none"> <li>• Underpinning principles are the same</li> <li>• Children and young people at the centre</li> <li>• Co-production with children, young people and families</li> <li>• Early identification and support can prevent crisis</li> <li>• Supporting children and young people to have a good life.</li> </ul> <p>NNPCF are working closely with SEND programme leads nationally, in regions and locally and in doing so are promoting the recommendations and principles of this guideline.</p> <p>NNPCF are working at a local, regional and national level on the Transforming Care agenda.</p>
2	Short	8	27-29	<p>The NNPCF is concerned that many Local Authorities and CCGs do not have accurate data relating to actual (or likely) current and future local service needs for children and young people with a learning disability and behaviour that challenges.</p>

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				<p>Many JSNA do not focus on and plan for the services required children and young people let alone children and young people with a learning disability or behaviour that challenges. Research by the Council for Disabled Children and the True Colours Trust '<i>Understanding the needs of disabled children with complex needs or life-limiting conditions: WHAT CAN WE LEARN FROM NATIONAL DATA?</i>' This research asks how we can plan to meet people's needs if we don't know what they are. The report states that there are growing numbers of disabled children and young people with complex needs and/or life-limiting conditions in the UK. These children, and their families, need support from statutory services in health, education and social care. It argues that there is a data challenge. "<i>Local authorities and providers do not have the data that allows them to adequately plan and commission services for these children and young people. The national data set on disabled children is inadequate: it has gaps, anomalies and inconsistencies. It is unfit for purpose. There is growing acceptance of the need to integrate and plan holistically for children and young people's needs.</i>"</p> <p>Parent carer forums are working with their Local Authorities to prepare and review the Local Offer.</p>
3	Short	9	5-7	<p>The NNPCF fully supports the holistic approach to assessing needs across education, health and social care through the EHC Needs assessment and plan. Parents value early identification and intervention. Across our regions there is mixed evidence of Local Areas using the outcomes and data from plans to jointly commission services. PCF will continue to work with their Local Areas to ensure that this happens.</p>
4	Short	9	9-11	<p>The NNPCF are concerned that not all LAs have an 'at risk register' in place and are using this information to plan services.</p>
5	Short	9	9-16	<p>Through our involvement in the SEND Regional Lead work the NNPCF are aware of some good examples of integrated and joint commissioning which are outcomes focussed based upon the PFA life pathways. For example in the London Region LB Bexley and LB Greenwich. The NNPCF works to promote and share good practice across our networks.</p>
6	Short	9	17-25	<p>The role of a lead commissioner is very much welcomed. Across our regions forum report a lack of local and regional plans that have a single care pathway and point of access for children, young people and adults with a learning disability and behaviour that challenges and their families. PCFs are raising their concerns with their LAs and CCGs to make sure this is reflected in their local authorities' commissioning strategies.</p>
7	Short	10	2-15	<p>Quality assurance and accountability are really important to parent carers. In LB Bromley the PCF is currently involved in a project to co-produce and Outcomes Framework to promote a shared understanding of good, smart and holistic outcomes; commission services to meet individual outcomes across education, health and care, and require service providers/education settings to show evidence of achieving these outcomes.</p>
8	Short	10	19-22	<p>SEND COP 3.18 states that at '<i>a strategic level, partners must</i></p>

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				<p>engage children and young people with SEN and disabilities and children’s parents in commissioning decisions, to give useful insights into how to improve services and outcomes. Local authorities, CCGs and NHS England must develop effective ways of harnessing the views of their local communities so that commissioning decisions on services for those with SEN and disabilities are shaped by users’ experiences, ambitions and expectations. To do this, local authorities and CCGs should engage with local Healthwatch organisations, patient representative groups, <b>Parent Carer Forums</b>, groups representing young people with SEN and disabilities and other local voluntary organisations and community groups’.</p> <p>PCFs are actively engaged in this work across our regions.</p>
9	Short	10	27-29	As above
10	Short	11	3-29	The NNPCF is the independent national voice of parent carer forums. We aim to empower our members to ensure that their voices are heard at an individual and strategic level. We provide information and support to enable parents to be involved in decisions regarding their child’s support and care.
11	Short	12	25-29	The NNPCF welcome this person-centred approach. We work towards delivering better outcomes for families with SEND through a culture of participation and coproduction and as equal partners.
12	Short	13	29-30	As above
13	Short	14	9-27	PCFs are concerned about the lack of services to purchase with direct payments (market development) and the drive by some LAs to be a commissioning only authority and not provide services directly themselves.
14	Short	15	14-23	<p>In March 2016 the NNPCF published their set of national priorities. <a href="http://www.nnpcf.org.uk/national-priorities-report-burning-issues/">http://www.nnpcf.org.uk/national-priorities-report-burning-issues/</a></p> <p>This report sets out the “Burning Issues” i.e. the most common and current issues that forums were focussing on at the time and highlights the importance of getting services and support right for families and carers.</p> <p>PCFs offer information and support to families and carers of children and young people with a range of SEND (including learning disability and behaviour that challenges) and peer support.</p>
15	Short	16	26-27	PCFs are reporting that due to austerity that LAs are raising their thresholds to support services so that lower-level needs are not met.
16	Short	17	4	<p>The NNPCF submitted a response to the call for evidence for the The Lenehan Review into Residential Special Schools. <a href="https://councilfordisabledchildren.org.uk/help-resources/resources/good-intentions-good-enough-lenehan-review-residential-special-schools">https://councilfordisabledchildren.org.uk/help-resources/resources/good-intentions-good-enough-lenehan-review-residential-special-schools</a></p> <p>Most parents would like to see their child’s needs met locally. Experience of OOB residential placements is mixed. At a recent focus group facilitated by Bromley Parent Voice the following reasons were given for requesting an out of borough educational setting:</p> <ol style="list-style-type: none"> <li>1. lack of confidence in schools/staff knowledge and skills (including lack of awareness of CFA 2014)</li> </ol>

## Learning disabilities and behaviour that challenges: service design and delivery

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				<ol style="list-style-type: none"> <li>2. lack of confidence/trust in the offer of in borough schools (mainstream and special)</li> <li>3. lack of wider offer e.g. social/leisure opportunities, extended curriculum</li> <li>4. in house therapies and equipment</li> <li>5. special schools in borough not stretching children and supporting them to achieve outcomes/aspirations.</li> <li>6. refusal to amend policies (behaviour not seen as a reaction to unmet needs)</li> <li>7. attitude</li> <li>8. not a lack of money but what it is or is not used for - lack of accountability of public funds</li> <li>9. VFM - placement costs should be based on individual assessed need of each child not generic and measured against outcomes achieved.</li> <li>10. OOB schools treat parents equal partners - families feel listened to, supported and not judged</li> <li>11. lack of flexibility of approach, support and non-person centred</li> <li>12. lack of choice (particularly at secondary)) Need a 'middle ground' option.</li> <li>13. Physical environment and space (including class sizes)</li> <li>14. CYP are safe</li> <li>15. Residential option - to prepare for adulthood otherwise will cost LBB more and yp will be more vulnerable</li> <li>16. Ability to transfer skills, adapt curriculum and access local community</li> <li>17. holistic approach</li> <li>18. positive role models</li> <li>19. panel processes - placement decisions based upon availability of places not need</li> <li>20. lack of joint commissioning</li> </ol>
17	Short	17	18-30	Families report a reduction in 'offer' within children and young people services and a lack of provision in adult services. NNPCF are working with DfE and DH to highlight the gaps in provision particularly at transition from children to adult services.
18	Short	22	2-9	<p>Through their work with LAs to develop their Local Offer, PCFs are actively working to ensure that children, young people and their families know about and are able to use services to support promote their health and wellbeing. This includes helping people to make and maintain social networks in their community and take part in community activities.</p> <p>In 2016 PCFs from across England worked with their Local Authorities on the Social Care Innovation Fund programme. This project was to identify new ways of identifying and assessing social care needs for children and young people with SEND. In LB Bromley the PCF worked with the LA to develop an online assessment tool and a range of films to promote 'Time for Me'.</p> <p><a href="https://bromley.mylifeportal.co.uk/timeforme/ola/">https://bromley.mylifeportal.co.uk/timeforme/ola/</a></p>
19	Short	22	21	See Burning Issues report
20	Short	22	23-26	See Burning Issues report
21	Short	24	11-12	The practice of monitoring OOB educational placements varies

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				both across and within our regions
22	Short	24	18-19	Feedback from forums are that some OOB placements are not working towards the outcomes set out in the child or young person's EHC Plan. Monitoring and accountability needs to improve, however, some LAs are struggling to identify the resources to do this.
23	Short	24	23-30	The NNPCF are extremely concerned about the reduction in short break services due to significant cuts to Local Authority funding. In particular, forums have seen a reduction in overnight provision. Many forums report changes to eligibility criteria restricting access to vital support. Parents are concerned that short breaks are only available to those children and young people who are eligible for an EHC Plan and that where a child or young person is not known to social care, Little or no assessment is being undertaken as part of the EHC needs assessment to determine whether or not short breaks are required. Families are being signposted to universal services via the Local Offer and forums are seeing an erosion of short break services set up under Aiming High for Disabled Children.
24	Short	25	3-12	There is a duty for LAs to work with parents and carers of their Short Break statement. PCF are involved in this work.
25	Short	26		Where a child or young person's needs requires in patient setting, NNPCF would fully support the NICE recommendations. Where ever possible the cyp should be placed as close to home as possible and the named worker should support the cyp to maintain links with family, friends and local community.
26	Short	28	11	Add 'and families' SEND COP 3.18 states that ' <i>At a strategic level, partners must engage children and young people with SEN and disabilities and children's parents in commissioning decisions, to give useful insights into how to improve services and outcomes. Local authorities, CCGs and NHS England must develop effective ways of harnessing the views of their local communities so that commissioning decisions on services for those with SEN and disabilities are shaped by users' experiences, ambitions and expectations. To do this, local authorities and CCGs should engage with local Healthwatch organisations, patient representative groups, <b>Parent Carer Forums</b>, groups representing young people with SEN and disabilities and other local voluntary organisations and community groups.</i>

Insert extra rows as needed

### Checklist for submitting comments

- Use this comment form and submit it as a **Word document** (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- **Include page and line number** (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- **Do not paste other tables into this table** – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish

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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, comment forms **do not include attachments** such as research articles, letters or leaflets (for copyright reasons). We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.

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.