

Transition from children's to adults' services

Consultation on draft guideline – deadline for comments: 5pm on 22nd October 2015 email: Transitionsctoanice.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 these questions:</p> <ol style="list-style-type: none">1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.2. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)3. What are the key audiences we need to consider in structuring the guideline?4. At what age does transition planning start now?5. How often do review meetings happen at present?6. How should parents be involved in transition planning?7. Will these recommendations result in an impact on cost of services?8. Which of these recommendations would lead to additional costs?9. Will any of these recommendations lead to cost savings? <p>See section 3.9 of Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>
Organisation name – Stakeholder or respondent organisation (if you are responding as an individual rather than a registered stakeholder please leave blank):	Together for Short Lives

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Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.				
Name of commentator person completing form:		Patrick McKenna		
Type		[office use only]		
Comment number	Document (full version, short version or the appendices)	Page number Or 'general' for comments on the whole document	Line number Or 'general' for comments on the whole document	Comments 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.
Example 1	Full	16	45	We are concerned that this recommendation may imply that
Example 2	Full	16	45	Question 1: This recommendation will be a challenging change in practice because
Example 3	Full	16	45	Question 2: Our trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact.....
1	Full	14	3	Named workers (or transition co-ordinators) are very important: they enable young people to articulate their aspirations and to plan for services from the wide variety of agencies that they require in order to fulfil these aspirations. Named workers can also assist with funding issues and discuss the use of personal budgets with the young person.
2	Full	14	7	It is unclear who will fund the work of the named worker. Would this be the NHS, local authority or voluntary sector? This should be established in the guidance. Similarly, the guideline does not specify which adult service the responsibilities should be handed over to. Should this be health, social services or voluntary sector?
3	Full	14	10	While the recommendation states that the named worker should have an existing relationship with the young person, the guideline does not set out how the young person will be offered a choice to select their named worker. Furthermore, it should set out how existing staff will get extra capacity to deliver this additional workload.
4	Full	14	20	In order to discuss the young person's options with them and to effectively co-ordinate services on their behalf, the named worker may require training. The guideline should set out how this training will be provided and funded.
5	Full	16	6	We welcome the inclusion of co-production with the young person – this enables young people to engage with their care and enables services to learn what young people want and how they can adapt and improve their services.

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				However, it should be recognised that this vital cultural shift will require time and resources.
6	Full	16	12	When developing new tools to help young people communicate effectively with practitioners (for example web apps), these tools should be shared across disciplines, sectors and agencies. These will save time and costs, although they should not be offered at the expense of genuine co-production. Engagement is a critical part of the process.
7	Full	16	28	Not all young people, including many with profound learning disabilities, will be able to live fully independent lives. However, their individual needs and things that make them feel happy and fulfilled should be considered with them and their families.
8	Full	7	20	We support the comments submitted to this consultation by South East Strategic Clinical Network regarding the difficulties that young people experience entering further education. We concur with their suggestion that there should be greater flexibility for these young people in terms of registering with a primary care provider, so that if they wish to then they can remain registered with their GP at home while collecting prescriptions at university.
9	Full	20	23	We welcome the inclusion of training for those working with young people in transition. However, the guidance does not clarify who is responsible for ensuring that the training is consistent.
10	Full	9	4	The issue of developmental transition is problematic for young people with severe cognitive impairments. It is difficult to work towards preparing a young person and their supporting team to move on because 'letting go' becomes a grey area for parents and professionals. The guideline should set out that profoundly disabled young people should be treated as adults in terms their personal care and sexuality. They should also be treated as adults in a developmentally appropriate way by adult services.
11	Full	22	5	The proposed 'local, integrated youth forums' should link in to the Regional Action Groups that form Together for Short Lives' Transition Taskforce. This taskforce looks at practical ways to improve transition for young people for young people with life-limiting and life-threatening conditions. This includes looking at different ways of developing partnerships between children and young people's palliative care services and a wider range of services including social care, housing and employment.
12	Full	22	1	The existing 'Ready Steady Go' transition programme is a useful tool for healthcare settings. The Preparing for Adulthood programme, funded by the Department for Education, also provides useful resources.
13	Full	General	General	<p>The following audiences should be considered when constructing these guidelines:</p> <ul style="list-style-type: none"> • Young people, parents, carers: The guidelines should reflect the difficulty that young people with complex of life-limiting conditions face in finding services to transition to. This can be highly stressful and transition plans become futile if there are no services available that can manage their complex needs. • Service providers: Primary care, secondary care, tertiary care, voluntary services, wider agencies (social care, education, housing, employment). • Short breaks providers: the guidance should support age-appropriate short breaks for young people. These are critical for both the young person, as they help develop independence and social skills, as well as their parents, as it gives time to re-charge their batteries and spend time with each other or other siblings. • Commissioners: CCG, local authorities (children's and adults' services)
14	Full	10	11	Many young people value the input of their parents in their decision-making process. If it is the wish of young people

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				and their parents, information and advice should be provided to their parents well into young adulthood. Parents/carers are likely to remain significant carers for young people as they transition to adult services and often act in a 'keyworker' role.
15	Full	26	21	<p>Questions concerning the consequences and costs of inadequate transition services should include the cost of emergency hospital admissions when young people drop out of the system. There are also wider, indirect economic factors to consider, such as the increased likelihood of the young person entering education and subsequently finding paid employment. Additional factors to consider include:</p> <ul style="list-style-type: none"> • Equipment costs. Currently, made-to-measure equipment often has to be returned to children's services when a young person enters adults' services, even though the equipment fits them perfectly. Improved joined up working would reduce this waste. • Having a singular, national approach may reduce the cost of developing lots of different guidelines and approaches. <p>However, there are additional costs in implementing the recommendations of this guidance, including:</p> <ul style="list-style-type: none"> • Delivering comprehensive training • Funding for named workers (<i>see comment 2</i>) • Holding transition clinics • Time taken to co-produce services and engage with young people
16	Full	23	25	There remains a large degree of confusion around the language used in 'transition' and many people don't understand what this term means. Guidance should contain a simple explanation of the term, i.e. that it refers to the process of preparing and planning to move from children's to adult's services as well as the actual transfer itself.
17	Full	25	2	We welcome the intent to conduct further research in specific areas of transition services. However, young people need action to be taken now and so more services should be prototyped and piloted so that they can be evaluated – including their cost-effectiveness.

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 to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.

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- 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.