

Care and support of older people with learning disabilities

Consultation on draft scope – deadline for comments 5pm on 08/09/15

email: opld@nice.nhs.uk

Please note:		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. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.	
Please also consider:		Is the definition of learning disability used in the scope the most appropriate one? We have not used a specific age limit to define 'older'. Do you: a) think that we should use an age threshold / limit and b) if so what should that age limit / threshold be? What should prompt health and social practitioners to consider whether a person with learning disability is also experiencing issues associated with being an older person?	
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):		Care and Repair England	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):		Jane Minter	
Comment No.	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, 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	General	General	<p>The Care Act 2014 defines well-being to include the suitability of living accommodation.</p> <p>It expects local councils to ensure the integration of care and support includes housing. There is recognition that the suitability of living accommodation is a core component to enable people to live independently.</p> <p>As a result we ask that the guideline includes housing as an important consideration in the provision of care and support for older people with learning disabilities and their carers.</p> <p>We make the following general points on the importance of considering housing alongside care and support</p> <ul style="list-style-type: none"> •Many of the health conditions people face are exacerbated by poor and inappropriate housing and can be alleviated by improving and adapting people's homes. This factor should be considered in the provision of health and social care interventions to support wellbeing •Whilst we would not expect social care and health practitioners to deal with housing issues, per se, we would argue that housing needs to be considered in any social care assessment and that staff need to know about the common housing issues and who to contact locally to ensure that people's housing circumstances are addressed in so far as they impact on a persons' wellbeing. •There is an expectation in the Care Act that housing factors are a part of an integrated assessment. <p>Whilst the Context for the Scope identifies the importance of the contribution of housing as well as health and social care to people's wellbeing we believe references to – and consideration of – housing factors need to be more prominent throughout the Scope.</p>
---	---------	---------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Please add extra rows as needed

Please return to: opld@nice.nhs.uk

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

2	General	General	<p>We would like the Context for the work to be broadened to consider the issues for older people living in, and wanting to remain, in mainstream housing. Work we undertook in 2008 looked specifically at the needs of older people with learning disabilities living in owner occupied homes. We identified that support in undertaking both repairs and adaptations and advice and information can be significant in supporting people to live well at home. In our work we identified that people were not getting the practical and financial support that they needed and we set out an agenda to address the issues. This included crisis support as well as preventative services recognising this group in local care, health, housing and wellbeing strategies.</p> <p>The report can be found at http://careandrepair-england.org.uk/wp-content/uploads/2015/01/Living-on-the-Edge-final.pdf</p> <p>We appreciate that the section on the Context for the guideline (Chapter 3) recognises the number of older people living with learning disabilities who remain in a family home when parents have died. We would, however, like to see more consideration of the impact of people's housing circumstances and ways to provide practical help and support for older people with learning disabilities to repair, adapt and manage their homes.</p> <p>In meeting care and support needs we would want the quality and suitability of the home to be an important factor in delivering support for wellbeing. We have picked this up in specific comments on page 12.</p>
3	1	26	Add housing and environmental health services to the list
4	3	21	Change to health, social care and housing
5	3	23	Change to health, social care and housing
6	4	1	Change to health, social care and housing
7	4	20	Add housing related support including repairs and adaptations to the home
8	4	24	Change to health, social care and housing staff
9	5	16	Change to health, social care and housing needs
10	5	18	Change to health, social care, housing and other practitioners
11	5	26	Change to health, social care, housing and other practitioners
12	6	8	Change to health, social care and housing services
13	6	12	Change to health, social care and housing services
14	6	15	Change to health, social care and housing
15	7	16	Change to care, support and housing practitioners
16	7	18	Change to care, support and housing practitioners
17	7	30	Change to health, social care and housing related quality of life
18	11	16	Change to social and related housing needs

Please add extra rows as needed

Please return to: opld@nice.nhs.uk

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

19	12	10 – 21	<p>Many older people with learning disabilities will be living in mainstream housing often with parents or following their parent's death as recognised in the draft Scope. Increasingly they will be home owners and needing help to ensure their home remains suitable as they age.</p> <p>It would be helpful to determine the general housing circumstances and tenure of older people with learning disabilities broadening the point about housing and support needs to include practical support with repairs, improvements and adaptations as well as other support to help people to stay in their homes if this is their choice and to prevent an early move to residential care.</p> <p>Our report - Living on the Edge - produced in 2008, sets out ways to enable older people with moderate learning disabilities to live independently through housing and other interventions. This includes crisis as well as preventative support and advice and information as well as practical help.</p> <p>See http://careandrepair-england.org.uk/wp-content/uploads/2015/01/Living-on-the-Edge-final.pdf</p>
20	12	22 - 26	<p>We propose that the guidance also considers some of the more complex issues encountered by people with learning disabilities to ensure that the guidance offered in relation to care and support interventions addresses these specifically.</p> <p>Our work in 2008 (highlighted in the section above) considered specific support issues for those older people with learning disabilities who hoard, self- neglect and who are carers themselves. We would like the guidance to look at both crisis intervention and prevention strategies for people with these specific needs so adding these issues to the Scope.</p>

Add extra rows if needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- 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.
- 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

Please add extra rows as needed

Please return to: opld@nice.nhs.uk

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

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

Please return to: opld@nice.nhs.uk

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