

National Institute for Health and Clinical Excellence

NICE Quality Standards Consultation – End of Life Care

Closing date: 5pm – 22 July 2011

Organisation	Childhood Bereavement Network
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Are you happy to be named as a consultee to the Quality Standard on the NICE website? <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No	

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Please provide comments on the draft quality standard on the form below. When feeding back, please note the draft quality statement number and indicate whether you are referring to the statement, measure or audience descriptor.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the quality standard.

Please add rows as necessary.

Draft Quality Statement No.	Comments about statements, measures and audiences.
General	<p>This response is from the Childhood Bereavement Network (CBN) the hub for those working with bereaved children and young people. Hosted by the National Children’s Bureau, we have over 250 members across the UK, and support their work with essential representation and support.</p> <p>We welcome the draft Quality Standard. Our response is particularly concerned with those statements which are relevant to children and young people before and after the death of someone important in their lives. We know that such a death brings change and challenge to a young person, and can be devastating. Bereavement brings increased risks of poor outcomes, particularly to children and young people who are already in disadvantaged circumstances or who have experienced multiple losses.</p> <p>Bereaved children often fall between several policy responsibilities, and this has contributed to inconsistency in the provision of organised services for them across the UK. We estimate that around 31% of local authority areas in England lack an ‘open access’ service working across the whole area with children who have been bereaved through any cause (sudden as well as anticipated deaths).</p> <p>Even where these services exist, they would not have the capacity to meet the needs of <i>all</i> the children in their area: some that are long established and well known by local schools and the community estimate that they reach only 50% of their target population. Thus the likelihood of being proactively offered and accepting a service before or after the death of a parent or someone else important is still relatively low.</p>

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	<p>The recent final report of the Palliative Care Funding Review has excluded bereavement care from the tariff of palliative care, while stating that ‘it is important that universal access to these services is available for everyone if they need them’ and acknowledging our evidence that this is not currently the case. The report recommends that ‘bereavement support continues to be supported by both the state and society’ (Palliative Care Funding Review, 2011, p57). We are concerned that without further action, the report will allow inequalities in the provision of bereavement care for children to persist, or worsen.</p> <p>The Quality Standard will be an important lever to redress inequalities in service provision for bereaved children and young people. We have some general points to make in response to the draft, as well as comments on particular statements, measures and considerations of equality and diversity.</p>
Quality measures (p3)	The draft points out that there are limited outcome measures that can be used as quality measures. CBN is currently developing an outcome tool for use across interventions with bereaved children and young people, funded by the Department of Health. We would be interested in talking further with NICE to see if this could be incorporated into the measures used for the quality standard.
Cost impact and commissioning assessment	We are very interested in the cost impact and commissioning assessment mentioned on p5. We are hoping to develop a ‘cost avoidance’ calculator to demonstrate the savings that can be made by successful interventions with bereaved children, through avoiding the intervention of other services such as education welfare, child and adolescent mental health, drug and alcohol services. Again, we would be interested in talking further with NICE to see if this could be of use to the standard.
QS2 (description)	<p>Understandably, parents can struggle to have open, supportive conversations with their children when they are facing the death of someone important: dealing with the complexities of palliative care and managing changes to family routines can mean there is little time to talk about what is happening and reassure children about the changes they are facing, which can leave them anxious.</p> <p>There are emotional barriers to talking, too. Sometimes parents are worried about breaking down in front of their child or don’t want to upset them with hard news. The uncertainties of a journey through illness can leave parents struggling to give children clear and consistent information. Young people themselves say how they find it difficult to open up conversations and ask for</p>

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	<p>support because they don't know how to, or they are worried about upsetting people.</p> <p>When a death is not anticipated, it can be difficult to find the time to help children understand what is happening and what will happen next, yet young people talk about their need for choices about how to be kept informed.</p> <p>It would be helpful if the standard could include support to improve communication <i>within</i> the family, as well as between the family and professionals.</p>
QS4 (measure)	<p>We welcome the specific mention of children in this quality statement. It is not sufficiently clear here when the measure is referring to carers, when it is referring to families and when it is referring to both.</p>
QS4 (definitions)	<p>The definition of 'emotional and psychological support' could potentially be expanded. We would like to see more detail about how children and families will be assessed, and by whom, although it may not be appropriate to include this level of detail in the quality standard. We would like to be involved in conversations to develop an assessment framework.</p> <p>It would be helpful to link this standard more closely to statement 18, which currently makes no mention of how people's bereavement support needs will be assessed.</p>
QS5 (eq and diversity)	<p>As described above, children and young people have particular information needs when preparing for the death of someone important in their lives. These may include reassurance on some very practical concerns such as who will care for them when the person dies, as well as careful, age-appropriate explanations of specific terms or situations. It would be helpful if these particular needs were recognised in this section.</p> <p>There are a number of resources to help give information to children in this situation: these include a series of leaflets produced as part of the Liverpool Care Pathway http://www.mcpcil.org.uk/patients-carers/Patients-Carers-Supporting-Children.htm CBN also produces a set of 'Stepping Stones' cards to aid conversation between children and their supporters when someone important is seriously ill www.cbn.org.uk</p>
QS9	<p>This statement seems very closely related to QS4, but the detailed definition seems much more focused on spiritual support, while</p>

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(statement)	emotional support is perhaps covered under QS4. Some further work in aligning these two statements may be helpful.
QS17 (definitions)	<p>This section usefully outlines that ‘accessible information on the experience of bereavement should be provided to the bereaved’. In particular, adults who are grieving themselves while parenting bereaved children, may benefit from information about some of the common grief reactions their children may show. These can often be disconcerting to adults, in particular the speed with which children can move between different reactions. Basic information can be reassuring in itself, and can help parents to support their children more effectively.</p>
QS18 (measure)	<p>We welcome this measure. However, we would welcome a specific mention of the need for bereavement support for children and young people.</p> <p>The stepped approach to emotional and bereavement support may be useful, but we feel this needs further clarification. There are two separate issues included in the current proposed model: what level of support is provided, and who provides it. It may be helpful to separate out these two issues: at the moment it suggests that, for example, support from the voluntary, community and faith sectors is only at the level of ‘supportive conversations’ when in fact much of the support offered to bereaved children and young people from the voluntary sector is from highly trained and skilled professionals, and aimed specifically at improving outcomes for those children.</p> <p>In addition, the statement currently makes no mention of how people’s bereavement support needs will be assessed.</p> <p>At present, the description states that people will have access to emotional and bereavement support which may include being referred on to other services. It is not sufficiently clear from this quality statement where responsibility for commissioning and/or providing specialist, formal bereavement support services for children and young people sits. We would like there to be a responsibility on commissioners to commission services at every level for children and young people.</p> <p>CBN members believe that all children have the right to information, guidance and support to enable them to manage the impact of death on their lives. Following extensive consultation with bereaved children and young people, their parents and carers, and</p>

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	<p>service providers, we believe that the services that should be available in every area are:</p> <ul style="list-style-type: none"> • Information about how children grieve, what can help and what services are available • An easy to access consultative process to agree who and what could help a particular family • Support for parents and carers to help their children • 1:1 support and peer groups for children and young people • Outreach and specialist support for those who are vulnerable or traumatised. <p>To underpin this support, the local authority and health services should work with other services to make sure they know how many children and young people have been bereaved that year, and what services they need. They should also ensure that adults who work with children get training and support to understand how they might help someone who has been bereaved, and where to find extra support.</p> <p>CBN's Belief Statement outlines that any information, guidance and support offered to children should:</p> <ul style="list-style-type: none"> • acknowledge the child's grief and experience of loss as a result of death • be responsive to the child's needs, views and opinions • respect the child's family and immediate social situation, and their culture, language, beliefs and religious background • seek to promote self-esteem and self confidence, and develop communication, decision making and other life skills • be viewed as part of a continuous learning process for the child, contributing to the development of the child's

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	<p>knowledge and understanding as they grow into adulthood</p> <ul style="list-style-type: none"> • aim, wherever possible, appropriate and feasible, to involve family members, other caregivers and any professionals working with the individual child in a wider social context. <p>If this information, guidance and support is offered as a service by an organisation or in a professional context, it should be:</p> <ul style="list-style-type: none"> • provided by people who have had appropriate training and who are adequately supported • provided in an appropriately supportive, safe and non-discriminatory context • regularly monitored, evaluated and reviewed.
QS18 (eq and diversity measures)	We welcome the statement that this support should be offered to those bereaved suddenly as well as those bereaved through an anticipated death, as services may be less available in these circumstances. We would welcome a particular mention of children and young people’s needs here.
QS19 (statement)	We suggest inserting ‘and their families and carers’ after ‘people approaching the end of life’. The need for training and support in bereavement care has been mentioned through the document and should be specifically referenced here, as it is in the measure.
QS20 (definitions)	There is no mention of the need for the provision of staff trained and supported to provide pre- and post-bereavement care to carers and families, including children. This is a significant component of care around palliative and sudden deaths, and we suggest that it is inserted.
	<p><u>References</u></p> <p>CBN (2009) <i>Grief Matters for Children and Young People</i> London: NCB</p> <p>Kennedy, Vida L.; Lloyd-Williams, Mari (2009) Information and communication when a parent has advanced cancer. <i>Journal of Affective Disorders</i>. Vol 114(1-3), 149-155.</p>

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	<p>Palliative Care Funding Review (2011) <i>Funding the right care and support for everyone</i> London: Palliative Care Funding Review.</p> <p>Siegal, K; Karus, D; Raveis, V (1996) 'Adjustment of children facing the death of a parent due to cancer' <i>Journal of the American Academy of Child and Adolescent Psychiatry</i> 35: 442-450</p>

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