

Briefing for Lords Short Debate on Tuesday 14 March 2017

'Ensuring the Clinical Commissioners respect the undertakings made in *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*'

This briefing sets out the need for CCGs to step up their understanding of, and investment in, tailored support for the whole family where a child has a life threatening or terminal illness.

This is in line with the government's recognition of the need to support the whole family, the need for greater personalisation, and the importance of community based services.

Please could you consider making the following points in your contribution to this Short Debate:

- *The Government Response to the Review of Choice in End of Life Care* recognises that children's palliative care encompasses the whole family. The response also supports greater personalisation of services for children at the end of lifeⁱ
- Many hundreds or thousands of pounds are saved for CCGs for every family that receive tailored social care support when their child has a life threatening or terminal illness
- Yet non-clinical palliative care services have very little access to statutory funding of any sort, with services like Rainbow Trust Children's Charity receiving zero funding from CCGs across England, and just three per cent from local authorities in 2015-16.

Question: How will the Government support CCGs to recognise the benefits of funding vital, cost effective, non-clinical child palliative care services for the whole family, enabling families to cope more effectively with their situation and delivering both short and long term savings for CCGs?

Social palliative care is the essential support that a family needs, alongside medical care, to face each day as it comes. Rainbow Trust Children's Charity is the leading organisation providing children's social palliative care in England.

Since 1986, Rainbow Trust has provided emotional and practical support to families where a child has a life threatening or terminal illness, currently supporting over 2,000 families each year.

Nine teams of Family Support Workers support the whole family in a place of the family's choice, providing a bespoke service according to the family's needs.

Rainbow Trust Family Support Workers can:

- Take a sibling to school while parents are in hospital with their sick child
- Play with the sick child while a parent has a much-needed break
- Pick a family up at 6am to drive many miles to a hospital appointment
- Provide bereavement support to parents and siblings following a child's death.

Yet the importance of such non-clinical services for children and their families outside the traditional hospice setting is little understood, and is often overlooked by decision makers, commissioners and funders.

As a result, Rainbow Trust receives zero funding from CCGs, and is not eligible for the NHS England annual Children's Hospice grant.

1. The value of social palliative care alongside clinical care

- Children's hospices can provide state of the art facilities which give both children and their families a much-needed place to go for a break, or for additional nursing/ medical support. Their role will continue to be crucial as the number of children with terminal and life threatening illnesses growsⁱⁱ, with more children surviving birth and with medical technology, enabling children to live longer with their diagnoses or conditions.
- However, children and their families have needs every day, throughout the year, and they need support when they leave the hospital or hospice. Social palliative care services can give families a genuine choice about the place and type of care that they receive, as well as enabling families to cope better.
- A family whose child has a diagnosis of a terminal or life threatening illness faces immense stress and upheaval. Frequent hospital appointments or in-patient stays mean it is often necessary for a parent to give up work, adding financial worries, childcare, and logistical challenges to an already complex situation.
- Rainbow Trust is confident that its services are contributing to families coping better. A pilot project to monitor how families assess their ability to cope in five areas of family life, found that 100 per cent of families reported that their ability to cope improved in one or more areas, during six months of support in 2016.

2. How services are saving significant sums of money for CCGs

- Rainbow Trust provides a service which saves the CCGs, local authorities and wider society significant sums of money, since our support can help families to avoid reaching a breaking point.ⁱⁱⁱ
- Some of these savings are immediate and specific, such as enabling families to attend appointments they may otherwise miss. Other savings are longer term, such as support which contributes to families avoiding crisis situations with repercussions for their mental health, family stability, and security of household income.

Examples include Rainbow Trust's Family Support Workers ensuring that:

- NHS appointments are not missed by already stressed families
- Pediatric beds are freed up sooner because both medical staff and the family feel more confident that a child's condition can be managed at home
- Siblings can maintain their routines, stay in education, and manage their emotions, reducing referrals to CAMHS services
- The likelihood of family breakdown may be reduced.

In each case the savings can be calculated in hundreds or thousands of pounds.

3. Despite the savings that are enabled for CCGs, children's social palliative care services receive almost no public funding

- Rainbow Trust receives just three per cent of its income from statutory sources for providing a highly personalised service. The remaining 97 per cent of its income is raised through voluntary donations.
- In contrast, children's hospices received 22 per cent from statutory sources in 2015-16, of which 11 per cent came from CCGs. Adult palliative care charities received 30 per cent of their funding from statutory sources.^{iv}
- It is clear that if organisations like Rainbow Trust stopped existing, significant costs would be incurred by the health and social care system.

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ⁱ Government Response to *The Review of Choice in End of Life Care*, 2016, pages 36-38.

www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf

ⁱⁱ More than 40,000 children (0-19 years) were estimated to be living with a life-limiting or life-threatening condition in England in 2009/10, although more recent research in Scotland suggests prevalence is growing. See *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity*, Fraser et al, University of Leeds/Together for Short Lives, 2011.

http://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children_s_Hospices_UK_-_Ethnicity_Report.pdf

ⁱⁱⁱ Forthcoming report, *Hidden Savings: How Rainbow Trust Children's Charity is saving money for the health and social care system*, Rainbow Trust Children's Charity, 2017.

^{iv} *On the brink: A Crisis in children's palliative care funding in England*, Together for Short Lives, 2016. http://www.togetherforshortlives.org.uk/assets/0001/7464/Together_for_Short_Lives_Commissioning_and_Funding_Survey_Report.pdf