

Representation from Rainbow Trust Children's Charity to Treasury on forthcoming Comprehensive Spending Review

Introduction

1. A growing number of families care for a child with a life-threatening or life-limiting condition. The most recent academic research estimated there were 86,625 children with these conditions in 2017/2018.
2. This number is expected to rise by 11% by 2030.ⁱ
3. Factors behind this rise include more seriously ill babies surviving birth, and more children living longer with their serious conditions as a result of medical and technological advances.

The need for emotional and practical support when parents are caring for a seriously ill child

4. When a child's condition is serious but stable, some families will not need additional support, depending on the existing support networks of family and friends. However many families will benefit significantly from respite and short breaks because of the emotional and practical demands of caring for their seriously ill child.
5. Parental mental health can be seriously affected by many months or years of heightened anxiety about their child's condition.ⁱⁱ Siblings can experience a range of strong emotions and potentially negative impacts on their education and wellbeing.ⁱⁱⁱ In most families one parent is unable to maintain employment while acting as the main carer and accompanying a child to frequent appointments and treatment, which can result in financial strain.
6. Short breaks can take various forms, from a few hours in the family home or in the community, to a few days of overnight care for a child, with or without their family. The importance of short breaks and respite care for families was recognised in the government's 2016 statement: 'Our Commitment to you for End of Life Care: The Government Response to the Review of Choice in End of Life Care'.^{iv} This document sets out what commissioners should provide for children who need palliative care. The value of emotional and social support is also noted by NICE in its guidance for caring for dying infants, children and young people.^v

Investing in preventative support can save significant sums for the health and care system

7. Rainbow Trust Children's Charity provides emotional and practical support to families across England through six teams of Family Support Workers across England. These Family Support Workers provide tailored care for families which can provide a much-needed break for parents and siblings. Three years ago Rainbow Trust published a report, *Hidden Savings: How Rainbow Trust Children's Charity saves money for the health and social care system*.^{vi} This set out a conservative estimate that the charity's provision of emotional and practical support was saving at least £2 million each year

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- for the health and social care system by enabling families to cope better with the demands of caring for a seriously ill child.
8. Recent updated calculations show that, with the same methodology, in light of a significant rise in the number of families being referred to Rainbow Trust for support from 2017-2020, estimated annual savings for the health and social care system now total £3.9 million.
 9. Examples of savings include:
 - a. Supporting a family to manage their child's condition at home (therefore reducing the length of stays in hospital). **Example saving of £466 per night on a transitional neonatal care ward.**
 - b. Supporting families to keep up appointments (saving the cost of Do Not Attends), including those without transport or childcare, or those who are overwhelmed by multiple appointments with professionals involved in their child's care. **Example saving of £70-135 for each missed appointment with a clinician.**
 - c. Supporting parents who may otherwise require social services support if they were unable to visit a sick child or neonate or experienced mental health issues. **Example saving of £660 for three months of family support from social services.**
 10. There is also evidence that access to respite services may help to prevent family breakdown as a result of the high levels of stress that parents can experience.^{vii}
 11. Families caring for a seriously ill child have become yet more vulnerable as a result of the COVID-19 pandemic. Survey data and interviews have indicated that many families have felt more isolated because of the need to shield as a household for many months while losing both formal and informal sources of support during periods of lockdown.^{viii}

What needs to change

12. Despite recognition of its value by both the Government and NHS England, non-clinical emotional and practical support has historically been ruled out of scope for both national NHS England and local Clinical Commissioning Group palliative care funding streams.
13. At the same time Local Authority funding for short breaks and respite for families with a seriously ill child has been declining over the last decade, and varies across England. Freedom of information requests by Together for Short Lives in 2017 found that more than one in five (21%) local authorities did not commission short breaks for children with life-limiting and life-threatening conditions.^{ix}
14. Charities like Rainbow Trust have found it increasingly difficult to access Short Breaks funds, despite the benefits that can result for both family members and the health and care system. For example, there is often a narrow interpretation of a child being 'permanently and substantially disabled'. This appears to exclude children with life-threatening conditions such as cancer whose long term prognosis is unclear, and excludes providing a break for their healthy siblings. It is also our experience that Short Breaks are increasingly being limited to children with an Education, Health and Care Plan (EHCP) which not all seriously ill children will have obtained while their family are focussed on intensive medical treatment, for instance.
15. With rising numbers of families in need of respite services, both now and in the future, this comprehensive spending review provides an opportunity to reset budgets in order to ensure that families caring for a seriously ill child can access support at the most difficult of times.

Recommendations to Treasury

1. **Rainbow Trust backs the call by the Disabled Children's Partnership (DCP) for HM Treasury to fill the £434 million gap in funding for social care services for all disabled children in England and their families.^x**

This could be done by creating an annual ringfenced disabled children's grant for Local Authorities. Importantly the definition of 'disabled' should be broad enough to encompass all children with a life-threatening or terminal condition, to prevent some families being excluded from accessing the emotional and practical support that they need purely because of an inflexible approach to life-threatening conditions for which the prognosis is unclear.

2. **Rainbow Trust backs the DCP recommendation for the government to establish a Disabled Children's Innovation Fund.** This could help to fund organisations delivering ground-breaking support and approaches in early intervention, identifying needs before families' reach crisis point. This has the potential to save significant sums of money for the public purse by enabling families to cope better with the demands of their child's care and its impact on the whole family.

About Rainbow Trust Children's Charity

Rainbow Trust Children's Charity has more than 30 years' experience in supporting families when a child has a life-threatening or terminal illness. The charity supports families through six teams of Family Support Workers across England.

Emotional and practical support from a Rainbow Trust Family Support Worker can enable the whole family to cope better in the most difficult of circumstances, providing tailored support based on what the family would find most helpful.

In 'normal' circumstances, our support comprises of:

- one-to-one support for the sick child, at home or in hospital
- spending time with any healthy siblings, who may be struggling to understand what is happening or who may need transport to/ from school
- helping around the home, to reduce practical burdens on parents
- providing transport to and from appointments and treatment
- listening to parents as they share their concerns
- bereavement support.

Examples of Rainbow Trust's support since the start of the COVID-19 pandemic include:

- Family Support Workers have been providing regular video and telephone support to seriously ill children and their healthy siblings, to brighten their day and listen to their fears. Support includes sharing of competitions, exercise routines, interactive cooking sessions, and story times.
- Families who have been shielding have not always been able to access medicines and groceries. Family Support Workers have sourced and deliver the vital items they need to keep going, like medicines, milk, and nappies.
- Family Support Workers have delivered breast milk from new mothers to their babies on the neonatal wards in situation where they are separated and unable to visit because a mother is self-isolating.
- Family Support Workers continue to provide emotional support to bereaved parents whose babies and children have died before or during the pandemic, and whose

usual support networks and options for commemorating their child's life have been curtailed by social distancing and infection control measures.

Rainbow Trust was represented on the Expert Panel for the APPG for Children Who Need Palliative Care during its 2018 inquiry.

ⁱ *Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*, Fraser, L., Gibson-Smith, D., Jarvis, S., Norman, P. , Parslow, R., published by The True Colours Trust/ Together for Short Lives, April 2020. www.togetherforshortlives.org.uk/wp-content/uploads/2020/04/Prevalence-reportFinal_28_04_2020.pdf

ⁱⁱ *Parents Matter: The impact on parents' mental health when a child has a life-threatening illness*, Rainbow Trust Children's Charity, 2020, www.rainbowtrust.org.uk/parentsmatter

ⁱⁱⁱ *See Us, Hear Us, Notice Us: The case for supporting siblings of seriously ill children*, Rainbow Trust Children's Charity, 2018.

^{iv} *Our Commitment to you for end of life care: The Government Response to the Review of Choice*, Department of Health. 2016. <http://bit.ly/2oOU5fj>

^v *End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]*. The National Institute for Health and Care Excellence, 2016. <https://www.nice.org.uk/guidance/ng61>

^{vi} *Hidden Savings: How Rainbow Trust Children's Charity saves money for the health and social care system*, Rainbow Trust Children's Charity, 2017. www.rainbowtrust.org.uk/uploads/other/pdfs/Hidden_Savings_Report_Final.pdf

^{vii} *A national study of the impact on parental relationships of short breaks provided by children's hospices*, Julia's House/ University of Bournemouth, 2017, www.juliashouse.org/keeping-families-together

^{viii} *Feeling Forgotten: Parental mental health concerns exacerbated by the COVID-19 pandemic whilst caring for a seriously ill child*, Rainbow Trust Children's Charity, 2020. www.rainbowtrust.org.uk/feelingforgotten

^{ix} *Commissioning children's palliative care in England: 2017 edition*, Together for Short Lives. 2017. <http://bit.ly/2MbiE4O>

^x *The Secret Life of Us Campaign: The Case for a Disabled Children's Fund*, Disabled Children's Partnership, 2018. <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2018/07/Case-for-a-Disabled-Childrens-Fund.pdf>