

Written evidence submitted by Rainbow Trust Children's Charity to Treasury committee inquiry on the Government's coronavirus financial package

The following submission addresses the question of whether the Government's response to the coronavirus is sufficient, and what are the areas where more support is needed.

Introduction

1. Supporting the national response and helping vulnerable people to cope is the top priority but charities cannot do this if they are on the brink of financial collapse.
2. Rainbow Trust Children's Charity provides emotional and practical support for more than 2,500 families each year who have a life-threatened or terminally ill child. This support is provided by eight teams of Family Support Workers across England.
3. Our Family Support Workers are Identified as 'key workers' in the Covid-19 crisis. Their support is continuing in any way possible at this time.
4. Recipients include families with children undergoing cancer treatment or organ transplants and those with compromised immune systems, all of whom must now self-isolate for 12 weeks to shield themselves.

Risk of charity being forced to close

5. Rainbow Trust receives no government funding and relies almost entirely on the generosity of the public, but all our fundraising events have been cancelled and our two shops have closed. Statutory funding came from just two local authorities in 2018-19, and made up just 1.2% of annual income.
6. After the March payroll Rainbow Trust is expected to go into overdraft and will draw upon its limited reserves. Our reserve policy is to hold a minimum of 3 months operating costs as reserves. These are under pressure, due to all our fundraising events being cancelled. Reserves currently represent only two months of operating costs and are also dependent on stock market fluctuations. The charity is therefore facing the reality that it might not survive.
7. Last week the Chief Executive had to tell the charity's 104 staff that they could lose their jobs. For our frontline Family Support Workers this means that the already scared, anxious and vulnerable families they are supporting will be left to cope alone.
8. As we understand the situation, the 80% of salary covered by government will not include any staff who continue to work but only those whom we plan to make redundant or put on unpaid leave. This scheme is therefore of limited value for the charity if it is to continue to provide support to families who need it more than ever in the current circumstances. We need immediate support to pay staff so we can continue to provide family support, rather than 'furloughing' staff and ceasing to provide a much-valued service.
9. All the families whom Rainbow Trust provides support to are already in that unimaginable situation that their child may die before them. Families tell us that Rainbow Trust Family Support Workers are sometimes the only trusted constant in their lives. The impact on parental mental health of withdrawing this support overnight would be enormous, as well as the ending of practical support from a trusted support worker with whom a relationship has been established.

Vulnerable families need support more than ever

10. Our Family Support Workers are needed more than ever by families whose daily lives were already extremely challenging before the outbreak of the pandemic. Family Support Workers are responding with passion, creativity and humility to support families both in person, wherever they can, and virtually, using WhatsApp, video calls and phone calls.
11. Examples of recent support include:
 - With outpatient and routine appointments being cancelled, families are no longer able to receive immediate advice and guidance from their clinical team, but Family Support Workers continue to be the bridge between hospital and home, relieving pressure on vital NHS staff by giving emotional support to worried parents who have nowhere else to turn.
 - Sibling support has always been a significant part of Rainbow Trust's support for families. With schools being closed, siblings of seriously ill children have lost an important outlet, where they would have normally been distracted or comforted by classmates and teachers. Family Support Workers are now giving regular video and telephone support to these siblings, to brighten their day and listen to their fears. Support includes sharing of competitions, exercise routines, interactive cooking sessions, and story times.
 - Where families used to be able to get their medicines and groceries relatively easily, they are now isolated and stuck at home, and Family Support Workers are working hard to source and deliver the vital items they need to keep going, like medicines, milk and nappies.
 - Family Support Workers are delivering breast milk from new mothers to their babies on the neonatal wards in situation where they are separated and unable to visit.
 - For some parents whose children have recently died, their Family Support Worker is the only lifeline and emotional support available to them as they face the deeply distressing prospect that they do not know when or how they can hold a funeral for their child.
 - Family Support Workers are currently providing emotional support to isolated bereaved parents whose babies and children have very recently died who may have very few sources of support.

Value of Rainbow Trust services to public sector

12. 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.*ⁱ This set out a conservative estimate that the charity was saving at least £2 million each year for the health and social care system by enabling families to cope better with the demands of caring for a seriously ill child.
13. Examples of savings include supporting a family to manage their child's condition at home (therefore reducing the length of stays in hospital); supporting families to keep up appointments (saving the cost of Do Not Attends) and 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.
14. 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 year on year, estimated annual savings for the health and social care system now total £3.9 million.

Urgent action required from government

15. A number of measures to ensure support for charities were set out a letter to the Prime Minister from a cross-party of MPs on Saturday.
16. Rainbow Trust strongly supports the contents of that letter, and would especially value action on the first two policy asks that MPs set out:
 - i. **Immediate emergency funding** for frontline charities, voluntary organisations and social enterprises who are supporting the response, especially where these are alleviating pressure on the health service or providing support to people suffering from the economic and social impact of Covid 19.
 - ii. **The provision of a ‘stabilisation fund’** for all charities, voluntary organisations and social enterprises to stay afloat and continue operating during the pandemic.
17. Supporting the national response and helping vulnerable people to cope is the top priority but charities cannot do this if they are on the brink of financial collapse. Without immediate and emergency funding, and the provision of a stabilisation fund, there is a risk that charities like Rainbow Trust will cease operation at a time when their support is of most value to families who will often have children in high risk groups and/ or for whom self-isolation is necessary for the next 12 weeks.

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 supported more than 2,500 families last year through eight 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.

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

Submitted by: Sophie Dodgeon, Policy & Campaigns Manager, on 23rd March 2020.

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