Rainbow Trust Children's Charity
Submission to APPG on Hospice and Palliative Care: Improving access to hospice and palliative care inquiry

Rainbow Trust Children's Charity provides emotional and practical support to families where a child has a life threatening or terminal condition, through eight teams of Family Support Workers across England.

Our service falls within the World Health Organization definition of palliative care which includes improving the quality of life of patients and their families and addressing their psychosocial needs.

Our aim is to enable families to make the most of their time together. Each family is paired with a dedicated expert Family Support Worker who supports the whole family in the place of their choice, providing a bespoke service from diagnosis, through treatment and bereavement. Family Support Workers fill in the gaps between the hospital and hospice, and help link services together.

1. What are the experiences of people and their families who have been unable to access hospice and palliative care, and what barriers did they face?

While some families may feel able to cope with their situation, some will not. Rainbow Trust supported just over 2,300 families in 2016-17, only a fraction of families who could benefit from our model of support may be accessing it.[1] More children are surviving birth and living longer with serious and complex conditions because of advances in medical technology.

We can only hypothesise the experiences of families whom we do not support, but research suggests family members experience stress and anxiety as they care for a seriously ill child, which can result in parental break up and feelings of isolation when support is lacking.[2] The burden of care and attending frequent appointments may bring financial hardship.[3]

Accessing emotional and practical support can enhance a family's ability to cope. Families supported by Rainbow Trust self-assess their ability to cope in six areas of family life at six monthly intervals.[4] 80 per cent of families taking part in this process

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[1] 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*, University of Leeds/ Together for Short Lives, 2011, http://www.togetherforshortlives.org.uk/resource/leeds-data-study/ More recent research in Scotland: *Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study),* University of York, 2015, https://www.chas.org.uk/news-articles/children-in-scotland-requiring-palliative-care-chisp-report

[2] See, for instance, *A national study of the impact on parental relationships of short breaks provided by children's hospices*, Julia's House/ University of Bournemouth, 2017, https://www.juliashouse.org/keeping-families-together and *Hidden Lives*, Together for Short Lives, 2018 http://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/180312-Report-on-Family-Survey-and-Misconceptions.pdf

[3] See for instance, *Cancer Costs*, CLIC Sargent, 2016 http://www.clicsargent.org.uk/content/cancer-costs Families reported an average additional monthly expense of £600 during treatment.

[4] See http://rainbowtrust.org.uk/our-impact/measuring-our-outcomes

in 2017 reported an improvement in their quality of life, for example. Other feedback from families and referrers indicates that the service is felt to be invaluable.

With no other services providing the same model of support, it is reasonable to assume that families in parts of England with no local Rainbow Trust team may be receiving little support outside of hospital and hospice settings and may be experiencing higher levels of stress as a result.

2. What are the factors that lead to unequal access to hospice and palliative care?

a) Funding and location

Local Authority Short Breaks funds provide our only statutory funding - comprising just three per cent of our total income, and hindering equal access to our services.

More than one in five Local Authorities were failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions in 2017.[5] Access to some forms of clinical care, such as out of hours care or community nursing, depends on decisions by Clinical Commissioning Groups (CCGs). Staffing shortages may also mean care is not available even if commissioned.

Access to overnight stays in hospices, and related family support services, will vary according to location. Travel time may be a barrier, with rural or island locations especially problematic.

b) Medical diagnosis

A child's diagnosis can influence access to care. For instance, cancer patients can receive support from Paediatric Oncology Outreach Nurse Specialists (POON nurses). In contrast, children with undiagnosed genetic conditions can find it harder to access palliative and hospice care.

In 2016, eight per cent of the children supported by Rainbow Trust had an undiagnosed condition. A 2016 survey found that 73 per cent of respondents without a diagnosis (all ages) felt it had been a barrier to accessing treatment.[6]

c) Parental reluctance to request help

As one parent explained, '*It's a big step for families to acknowledge they need help. There is a lot of pride.'*

Some families prefer care to be provided by family members for as long as possible. Occasionally religious beliefs mean a child's illness is felt to be a source of shame and stigma.

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[5] *Commissioning Children's Palliative Care in England,* Together for Short Lives, 2017, http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/commissioning-england-2017/

[6] *The Rare Reality – an insight into the patient and family experience of rare disease*, Rare Disease UK, 2016, https://www.raredisease.org.uk/media/2361/patient-experiences-2015.pdf

d) Minority ethnic and disadvantaged groups

Black and minority ethnic (BME) groups are under-represented among the families that we support. Travelling families and homeless families or those in temporary accommodation are also likely to be under-represented.

3. What actions are palliative care providers, commissioners and policy makers taking to improve access to hospice and palliative care?

a) Rainbow Trust teams monitor the characteristics of caseloads to inform outreach initiatives. Teams work with refugee families and families seeking asylum, helping parents digest information and attend appointments they might otherwise miss, because of language difficulties and the lack of a permanent address.

The Greater Manchester team has built relationships with local mosques and BME agencies, e.g. distributing leaflets after Friday Prayers to increase awareness of our sibling support, and taking part in bereavement training at an Islamic Centre to gain understanding of attitudes to death and bereavement. The Central London team works with Gardens of Eden, Europe’s biggest Muslim cemetery, to support families with end of life wishes.

b) Partnership working can increase access, e.g. a co-funded role specifically supports children with cardiac conditions at the Evelina Children’s Hospital.

c) Increased use of trained volunteers is expanding practical support, e.g. volunteer drivers can take families to appointments, and a Bristol project provides practical support to families at home.

4. What barriers do palliative care providers, commissioners and policy makers face in improving access to appropriate services?

a) Statutory funding

Access to our services is hindered by the lack of incentives to commission non-clinical services, despite the evidenced benefits. Rainbow Trust conservatively estimates that it saves the health and social care system at least £2 million each year.[7]

Short Breaks funding is increasingly difficult to secure. Sometimes a child must have an Education, Health and Care Plan, which seriously ill children often do not. Increasingly, Local Authorities prefer to have a Framework Agreement with a number of providers. Under these Rainbow Trust does not know how many referrals to expect, hindering budget allocation.

Our service is ineligible for NHS England’s Children’s Hospice Grant Programme. No local CCGs provide funding, and the drive towards personal budgets may compound the challenge for charitable bodies which prioritise families according to need rather than ability to pay.

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[7] *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/hidden-savings

b) Lack of data

Additional data collection, research and analysis is required to understand prevalence within each local area, and the gap between service use and prevalence among children from under-represented groups.

c) Low awareness of suitable services among professionals

Families often report a delay in hearing about relevant palliative services. It is apparent that many professionals do not know where best to direct families for support.

5. What national, regional and local levers would support improving access to hospice and palliative care?

a) Establishment of national data collection and analysis to understand the prevalence of life threatening and terminal conditions among children. This is essential for effective commissioning.

b) Ending the artificial divide between clinical and non-clinical funding, including opening up the NHS England Children's Hospice Grant Programme to non-clinical services. Shared health and social care budgets could ensure a more efficient resource allocation.

c) Ensuring parity of statutory funding for children's and adult palliative care services. Children's hospices receive on average 22 per cent of their income from statutory sources. Adult hospices receive an average of 30 per cent.[8] Voluntary community-based children's palliative care providers receive far less. In contrast, Scotland has achieved parity between adult and children's hospice funding.

d) The Department for Health and Social Care and NHS England should develop a system to monitor how CCGs and Local Authorities are supporting children's palliative care in accordance with their legal duties.

e) Targeted initiatives could increase referrals and boost uptake of services by under-represented groups.

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[8] See *On the Brink: a crisis in children's palliative care funding in England*, Together for Short Lives/ Hospice UK, 2016, http://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/statutory-funding-in-england/