

## Westminster Hall debate on 'Support for young carers' Tuesday 12<sup>th</sup> February 2019

- Will the Minister acknowledge the importance of sibling support in the community as a route to supporting young carers?
- Will the Minister encourage the commissioning of sibling support for young carers by Local Authorities as part of their Short Breaks offering?

### About Rainbow Trust Children's Charity

Rainbow Trust was established in 1986. We provided emotional and practical support to more than 2,500 families with a child with a life threatening or terminal condition across England last year, through eight teams of Family Support Workers.

This often includes support for brothers and sisters that would meet the definition of being a Young Carer.

Support is offered in the home, community or hospital as required. We pair each family with an expert Family Support Worker who becomes a trusted and constant person in family life. Our support enables parents with a seriously ill child, and their siblings, to make the most of time together; providing expert practical and emotional support, where they need it, for as long as it is needed.

### Sibling carers as young carers

Rainbow Trust's most recent report, *See Us, Hear us, Support Us!*, sets out the case for supporting the siblings of seriously ill children. Such support can enable brothers and sisters to learn important coping mechanisms, find an outlet for their strong feelings and worries, and keep up their school work.

- **Increased prevalence of serious illness in children and young people**

Our estimate is that at least 32,000 families in England with a seriously ill child have one or more siblings. This is based on academic data from 2009-2010. The true figure in 2019 is likely to be significantly higher in light of more babies surviving birth with a serious condition, and more children and young people living longer with life threatening and terminal conditions owing to medical advances.

- **Risk of sibling carers not being identified**

Rainbow Trust believes many of these siblings would meet the criteria for being identified as a young carer but are being missed out of official data. This is because, focused on the sick child's treatment and experiencing high levels of stress and anxiety, parents will often not consider their healthy child or children to be young carers. The child or young person themselves may not identify themselves in this way, despite the impact of the situation on their daily life, education and wellbeing.

- **Limited funding for supporting young carers outside of school setting**

Recent recognition of the value of supporting this particular group of sibling young carers with a seriously ill brother or sister<sup>ii</sup> has not been translated into funding.

Many local authorities have reduced funding for services such as Short Breaks because of budgetary pressures.

At the same time, even if a school is aware of a child being a sibling carer, their budget to support the child will depend on what competing demands they face in spending their Pupil Premium.

### **Examples of support for sibling carers which save money for the education, health and care system**

- In a recent example, Rainbow Trust support enabled a sibling to attend school on 32 occasions. Her parents would otherwise have been unable to send her to school because the mother needed to be with her terminally ill younger sister for appointments and in-patient treatment, and the father's work required being some distance from the family home during the working day.
- In another example, a parent is confident that Rainbow Trust support prevented her teenage daughter from requiring counselling. Her daughter felt isolated and alone when her brother was suddenly diagnosed with cancer, and she had to move in with grandparents initially.

The sister said: *'When James got ill, I felt isolated and like I couldn't talk to anyone. I didn't want to make mum worry more, so I didn't say anything. When [the Sibling Support Worker] came, she made me feel that I could open up to her and trust her. We also get to go on days and evenings out. It's really good seeing other brothers and sisters who are the same and understand.'*

Her mother said: *'At any other time, if we, as a family, were met with this level of trauma we would be there for our kids. The nature of sudden, life threatening illness in children means that we [parents] cannot practically be there for all of them.'*

The sister received two years of support from Rainbow Trust during her brother's cancer treatment, and benefitted significantly from having someone outside the family to open up to.

- Another parent who valued access to sibling support explained: *"There's only one of you and I found it was one of the hardest things to juggle, I felt a lot of guilt towards the other siblings, I felt they were very much missing out, whether it was due to hospital stays or the strict routine I had at home."*

### **Rainbow Trust's support**

Support can include:

- talking to brothers and sisters who struggle to understand what is happening
- helping siblings to attend school
- playing with the sick child or their siblings
- drop in groups for siblings and days out in school holidays
- helping families at home with practical tasks
- assisting with transport to and from hospital appointments

- emotional support
- attending important medical appointments with parents
- helping a family make memories and plan for end of life.

Siblings who took part in group activities and days out with Rainbow Trust in 2018 said:

*'It gives kids like us a break coming out with Rainbow Trust, to forget about what's going on and feel normal like my friends.'*

*'I like how we make friends and see them at the hospital now, it makes it less boring.'*

*'I've met lots of new friends through going out with Rainbow Trust.'*

Rainbow Trust is urging the Department of Health and Social Care and the Department for Education to make sure that children and young people in all parts of England have access to high quality sibling support, as and when required, before their education, mental health and wellbeing, are more seriously affected.

### **An inequitable funding base**

- NICE guidance recognises the importance of supporting siblings<sup>iii</sup> in the context of end of life care for an infant, child or young person, but at present there is little evidence of this support being translated into commissioning decisions.
- Rainbow Trust received just 2.4 per cent of its income from statutory sources in 2017-2018. This was from a decreasing number of local authorities as part of their funding for Short Breaks.
- As a non-clinical service Rainbow Trust does not qualify for the NHS England Children's Hospice Grant Programme, and we are not funded by any Clinical Commissioning Groups (CCGs).. We are unlikely to access any of the new NHS England funding for child palliative care announced recently in the Long Term Plan.
- Paradoxically, while the diverse ways in which a service like Rainbow Trust can support siblings, parents and the sick child will act to enhance their choice around the support that they receive, the same diversity makes it harder for the charity to meet the narrowly defined criteria for statutory funding or contracts.
- We do not know exactly how many families are struggling to cope, but we do know that with more equitable funding we could support many more sibling carers in more parts of England.

### **Contact information**

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<sup>i</sup> See *Us, Hear Us, Notice Us: The case for supporting siblings of seriously ill children*, Rainbow Trust Children's Charity, 2018. [www.rainbowtrust.org.uk/seeushearus](http://www.rainbowtrust.org.uk/seeushearus)

<sup>ii</sup> *End of life care for infants, children and young people with life-limiting conditions: planning and management*, NICE guideline NG61, 2016. [www.nice.org.uk/guidance/ng61](http://www.nice.org.uk/guidance/ng61)

<sup>iii</sup> *End of life care for infants, children and young people with life-limiting conditions: planning and management*, *ibid.*