

Children's, young people's and families' experiences of Rainbow Trust Children's Charity

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Introduction

Rainbow Trust Children's Charity provides family centred, emotional and practical support to families who have a child with complex and continuing care needs, disabilities or life threatening or life limiting illness. Support is available to all members of the family and can be provided in a number of settings, including home, community or hospital.

“When you have an ill child you find out who your real friends and family are. Everyone disappears. ... No one wants to babysit or help out” (M).

Who did the research study?

The research study was done by three researchers - Bernie Carter, Anne Hunt and Maria Edwards - from the University of Central Lancashire.

What did the research aim to do?

In this study we aimed to explore:

1. Satisfaction with how Rainbow Trust Children's Charity works with families;
2. Whether families benefit from receiving services from Rainbow Trust Children's Charity;
3. Any areas that people felt could be improved about how Rainbow Trust Children's Charity works with families.

In order to collect as many different views as possible we planned to invite all of the families who were using Rainbow Trust Children's Charity at the time we were doing the study to participate. We also planned to invite all of Rainbow Trust Children's Charity Teams and a range of professionals who have contact with Rainbow Trust Children's Charity (for example, people who refer families to the Trust) to participate.

This report is a summary of the research that we did for Rainbow Trust Children's Charity and it focuses on the information the families (children, young people and their parents) shared with the researchers.

How was the research done?

The research was carried out in three parts:

Part 1: A survey pack was sent to most families who were on Rainbow Trust Children's Charity's caseload at the time of the study. This pack included surveys for parents or carers, children, young people and siblings. We also sent survey packs out to all members of Rainbow Trust Children's Charity Teams and to professionals who referred families to the Trust. Anyone who wanted to take part was asked to fill in the survey and send it back to us.

Part 2: If some of the families wanted to be more involved in the study we invited them to share stories, pictures or poems about the way their lives had been changed by the service received from Rainbow Trust Children's Charity. They could do this by sending us their stories, poems and pictures by post or by email. They could also talk to us over the phone about their experiences of Rainbow Trust Children's Charity.

Part 3: We also visited families in four of Rainbow Trust Children's Charity teams and spent time with the Family Support Workers/Managers. This enabled us to observe the types of care and support the Family Support Workers provide



and to speak to some parents, children, young people and siblings about their views of the service.

Who took part?

55 families took part, 12 of whom were bereaved families.

27 children, 5 young people and 7 older siblings took part in the study.

21 staff members and 23 people who referred families to the Rainbow Trust also took part.

What did we find out?

We found out about the services that the parents, children and siblings thought were the most important. We also found out what they thought about the quality of the service and which services they used most or least frequently. Families and children told us about the ways in which the Rainbow Trust had helped and supported them and how it had made a difference to their lives

What did families say about Rainbow Trust Children's Charity?

The services used most frequently by non-bereaved families were 'activities with children and siblings', 'help with transport' and 'support for parents and family'.

For bereaved families, 'emotional support', 'practical support and advice' and 'information and support for the family' were used most frequently. One bereaved mother explained how the Rainbow Trust were:

"really good at such a difficult time. It's rare to find people with that kind of experience (experience of parents losing children). Their experience is what makes them so good at helping you. Friends and other people don't really know what you are going through".

In terms of quality of service, all aspects of Rainbow Trust were generally rated as 'good' or 'very good' by non-bereaved families, with 'helpfulness', 'reliability', 'knowledge and skills of the Family Support Workers' being most highly rated.

From the perspectives of bereaved families, Rainbow Trust delivers a 'very good' service, particularly in terms of the 'practical support provide to families' and the 'emotional support of parents'.

What did children and young people say about Rainbow Trust Children's Charity?

Children and siblings described their Family Support Workers as being 'happy', 'kind' and 'smiley' and were emphatic about the 'fun times they had together' and how they enjoyed playing 'games', 'cooking', 'making things', 'drawing and singing' and 'trips out'. For young people, the 'reliability of their Family Support Worker', and the 'support derived during hospital appointments and when in hospital' were rated as 'very good'. One of the older siblings explained that:

"They have helped a lot to me and my family. We are not stressed anymore and not fighting.....". [They went on to explain that one of the things that had changed for their family was] "kindness to each other".

How do Family Support Workers make a difference?

The presence of the Family Support Workers in families' and children's lives was a central part of the service provided, in the sense of 'being there' and also in the sense that they were available and accessible. We found that the Family



"[It] really helped. Rainbow Trust allowed us to have some type of normality instead of sitting at home on your own all the time. It was a chance to get out of the four walls. ... 'Being able to do some things together was fabulous. It was a real benefit to feel like a real family. Being able to go out. You can feel 'imprisoned in your own home. Things can happen quickly on the 'medical side' and when there is just one person and you are away from home it is difficult. (Our daughter) could 'turn quite quickly' and need to go to hospital immediately. It's daunting"(F).





Support Workers helped families in three main ways:

- * **Encompassing and embracing;**
- * **Befriending and bonding; and**
- * **Accompanying and enduring.**

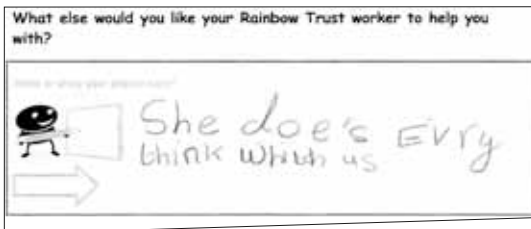
Encompassing and embracing

The Family Support Workers encompassed children and families, helping to lessen the trauma and disruption caused by illness. This was achieved by

supporting families practically, emotionally and socially in a way that was flexible and responsive to children’s and families’ individual needs.

Each family’s circumstances was different which meant that support was tailored to their particular needs. Reliable support was greatly appreciated as one of the families described:

“without the support of the Rainbow Trust our family would be in a state of crisis. [It’s] the only support our family receives on a regular basis and what we can rely on getting”.



The children and young people appreciated the support they gained from their Family Support Worker and could not think of anything else their Worker could help them with.

The young people and older siblings explained that their Family Support Worker had made a lot of differences for them and their family. One young person explained the main difference was “taking me out in order to give the family peace and quiet without me”.

Another went on to explain that they had made a big change to “MY LIFE! And family life as well”.



Many families described their children’s illness as being a journey, consisting of different stages. The Family Support Workers provided support through all the different stages, accommodating and responding to the families’ and children’s changing needs throughout the journey. One mother explained:

“We are quite new to Rainbow Trust but I feel sure that the service will change as my son’s needs change over time. ... It seems to be flexible and changing to what we want and need”.

The bereaved families found that the ongoing support provided by the Family Support Workers was invaluable. One mother commented that “they seem to know where you are in the (bereavement) process”.

Befriending and bonding

As the Family Support Workers encompassed and embraced families, they bonded with and befriended the families and children they cared for. One mother described how her:

“children love (FSW) to bits. They love them to come. They say “Is [FSW] coming tomorrow?” They count down the days to them coming...They do nice things. Have fun...They like it when they come”.

This was confirmed by the children in their responses and drawings. Children talked about the things they do with their Family Support Worker “Play games – sing – laugh – have fun – draw/arts/crafts – cinema – McDonalds – and lots, lots more”.

This enabled trusting relationships to grow and allowed the Family Support



Workers to gain a unique knowledge of the families and children. Frequently, families and children spoke about the positive, fun and supportive relationship they had with their Family Support Worker, describing the closeness they enjoyed together and the support they derived from them. One mother explained that her Family Support Worker is:

“different to a friend. She really cares but she is [a] detached, professional. My family and friends are good but they have an emotional vested interest in the situation. Sometimes you can't say things in case they break out crying. (And) sometimes you want practical solutions and not an emotional response”.



Some of the children also expressed the feeling that their Family Support Worker was part of the family “She is like an auntie but different. I wish I had an auntie like her that cared a lot”.

Accompanying and enduring

Throughout the different stages of the journeys of children's illness the Family Support Workers accompanied the children and families and endured the journey with them. One of the families explained:

“Rainbow Trust have made a big difference as before meeting them I used to struggle to get to my daughter's appointments. But now I am always able to get to my daughter's appointments on time and have help to carry her things without rushing around and getting late or into a panic...They are always on time and take the worry out of travelling with a sick child on public transport in sometimes horrible weather”.



Rainbow Trust Children's Charity supported and were “there” through many of the different situations and crises that families faced. The presence of the FSW enabled children and families to endure the emotional roller coaster of illness. As one of the young people explained “I get less stressed and ill when (FSW) takes me [to my appointments/hospital]”.

Areas for consideration and improvement

Although the children, young people and families were overwhelmingly positive about the work of Rainbow Trust Children's Charity they did suggest areas for improvement. These included: raising the profile of Rainbow Trust Children's Charity so it is more widely known; reviewing the on-call system to be more accessible for families and considering training the Family Support Workers so that they could care for children with medical needs.



Conclusion

We found that Rainbow Trust Children's Charity makes an enormous difference to families. The service is seen to be flexible, reliable and responsive and is unique in both its support of the whole family and by providing types of support not available from other services. This uniqueness enables it to fit effectively into the matrix of other services.

Rainbow Trust is committed to supporting families and helping families give their children childhoods that are as full of fun as they can be. Rainbow Trust seems to give families what they need and want. As a result, Rainbow Trust provides a service that is seen as priceless by many of the children and families.



Once a long time there was a boy called Samuel. his baby brother
was ill. So rainbow trusts help's them. and they have a nice woman helping
them. her name was Toni. one day Toni said who wants to see a movie. "me me me
id!" well what are we waiting for so we all jump into the car and we watched
Toy Story 3!!! it was funny but i cried when Buzz, Woody, Rex and
all of Woody's friends nemy was broken and then we had a madones
The
end

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