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RAINBOW TRUST CHILDREN'S CHARITY

The York Health Economics Consortium 2012 Final report

The Economic Impact of the Family Support Teams

Final Report

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Executive Summary

Overview

E.1: This Report has been written by York Health Economics Consortium for Rainbow Trust Children's Charity (Rainbow Trust). Rainbow Trust is a charitable organisation providing emotional and practical support for families who have a child with a life-threatening or terminal illness.

E.2: The Trust operates a number of Family Support Teams (FSTs) in England, each comprising a Manager and several Family Support Workers (FSWs). They offer the whole family individually tailored high quality support for as long as it is needed. This unique service is provided to the families in their homes and in the local community, and focuses on the needs of each family member, including the sick child, parents, siblings, grandparents and all extended family members.

E.3: Rainbow Trust is interested in exploring some of the economic and financial consequences of its work. The impacts may be felt by the families, providers of statutory services (such as the NHS and Social Services) or the wider economy.

E.4: The Report includes quantitative analysis of the activity and cost data for the FSTs in 2009/10 (the most recent year for which data are available). This material presents some unit costs, such as the cost per family and the cost per hour of support. It also considers how the costs are divided into 'care' and 'core' (i.e. central overhead) costs and how the FSW workloads are split across different types of support (these being generic FSW support; hospital support; sibling support; and bereavement support).

E.5: Telephone interviews were undertaken with the Managers of the FSTs to discuss the activities of the FSTs and to identify a wide range of adverse events that may have been prevented by their work. Although it is impossible to know what would have happened to a particular family in the absence of support from Rainbow Trust, experienced Managers and FSWs can draw on their professional skills and experience to identify what might have happened, such as the development of physical or mental health problems, or behavioural problems. Although working with an FSW does not guarantee that certain adverse outcomes – such as family breakdown – will not occur, it can reduce the risks of such events happening.

E.6: These adverse events might have resulted in costs being incurred by the families and the statutory sector. For example, families might have had to pay for transport to hospital visits and clinic appointments. The public sector might have incurred additional expenditure on health and social care, and on responding to educational and behavioural problems. This expenditure could have been associated with any family member, not just with the sick child.

E.7: The information from the telephone interviews was combined with material from a variety of published papers and reports. These were used to tabulate the potential cost consequences for the various stakeholders associated with the identified adverse outcomes that may have been prevented by the work of the FSTs.

E.8: The Appendix presents a review of recent relevant literature on the economic aspects of various models of care for managing children with complex needs and life-limiting conditions.

Summary of Quantitative Data Analysis

E.9: The quantitative data analysis considers activity and cost data for the FSTs in 2009/10. It shows that:

- The average caseload per FST was 95 families, with a range of 43 to 142;
- The average number of bereaved families in the caseloads was 12 (i.e. about one in eight, or 12.5%), with a range of 3 to 21 (7.0%-19.4%);
- The FSTs spent an average of 36.9 hours with each family (range: 16.1–91.1) during the year;
- The FSTs provided a total of 24,509 hours of work (with an average of 3,501 per FST);
- The FSTs spent this time providing four main types of support:
    - Generic support: 55.2%;
    - Hospital support: 30.0%;
    - Sibling support: 11.2%;
    - Bereavement support: 3.6%.
- The FSTs cost a total of almost £1.65 million (£1,648,506), of which £1.12 million (£1,122,056) was for care costs and £0.53 million (£526,450) was for core (central overhead) costs;
- 73.4% of the care costs were for people costs (i.e. staff-related), 20.4% for travel and motor costs, and 6.2% for establishment costs;
- Core costs accounted for almost one-third (31.9%) of total costs, with care costs accounting for the other two-thirds (68.1%);
- People costs, therefore, accounted for almost half (49.6%) of total costs;
- The overall budget for 2009/10 (£1,715,336) exceeded actual expenditure (£1,648,506) by almost £67,000 (3.9%), although there was considerable variation between the FSTs (ranging from a 10.0% overspend to a 15.1% underspend).

E.10: The following table summarises the key unit costs:

Unit Cost	Average for All FSTs	Range Across FSTs
Average care cost per family	£1,690	£1,061 - £2,678
Average care cost per support hour	£46	£29 - £66
Average total cost per family	£2,483	£1,513 - £4,070
Average total cost per support hour	£67	£45 - £94
Average total cost of generic FSW support per family	£1,370	£967 - £3,370
Average cost of hospital support per family	£745	£132 - £1,737
Average total cost of sibling support per family	£278	£77 - £532
Average total cost of bereavement support per family	£90	£17 - £148

E.11: The data analysis shows some marked variations across the FSTs. For example, although the average total cost per family (which includes care costs and core costs) is almost £2,500, it ranges across the FSTs from about £1,500 to just over £4,000. There may, however, be many valid reasons for these differences (such as Team size, area covered, and Team maturity).

E.12: The analysis of the cost data in the Report also shows the average costs of the different types of support provided by the FSTs, and how these vary across them. Although these costs will depend on the ways that the individual FSWs classify their hours of work (given that several types of support can be provided simultaneously), the analysis appears to reveal some interesting differences across the FSTs. For example, some FSTs only seem to provide limited bereavement support. This may reflect a need for some additional training in this area of support, or it may be due to the characteristics of the families being supported during the year by the FST, such as relatively few with children dying of terminal conditions during the year.

E.13: We suggest that Rainbow Trust explores these variations to see if there are any aspects where some FSTs could learn from the characteristics and practices of the others.

Potential Cost Savings

E.14: The discussions with the FST Managers highlighted some of the main benefits of their support (which are also supported by the literature review). As well as providing practical support with day-to-day tasks and activities, providing emotional support can reduce the relentless stresses and pressures of caring for a sick child. Such support may help to prevent family breakdown, which can have far-reaching effects on all members of a family.

E.15: Families with a sick child will face many financial pressures, especially if one or both parents have to reduce their hours of work or cease working completely. Support from a FSW may enable a parent to continue working, or reduce their need to take time off work.

E.16: Although we cannot identify the precise benefits of the support provided by the FSW, it is interesting to compare the average cost of support per family (i.e. £2,500) with some of the costs that may have been prevented by the support. It should also be remembered that this £2,500 will be spread over several family members – so the cost per person for a family of two parents and three children will only be £500. Furthermore, we know that all families working with Rainbow Trust (and all members of these families) will benefit in a variety of ways from their involvement.

E.17: Some examples of potential cost savings drawn from published research and other data sources (e.g. government websites) are presented below:

- Help with transport to and from hospital can save a family several hundred pounds over a period of time;
- Preventing the need for a GP visit because of concerns about physical and/or mental health can save about £85 per visit for the NHS (cost of consultation and prescribed medication);
- With an average cost per hospital bed day estimated as £250 to £300 (or possibly as high as about £450), a three-day stay in hospital can cost the NHS from about £750 to £1,500;
- A series of counselling-type sessions for mental health problems such as stress and anxiety can cost the NHS about £2,750;
- Visits to specialist mental health professionals can cost the NHS at least £250 per visit, and often considerably more;

- For example, the national average cost of a first outpatient mental health consultant appointment is about £436 (and £257 for follow-up appointments);

- Foster care for a child can cost an average of about £900 per week (or over £45,000 per year); this may be higher for a child with behavioural problems;

- Early recognition and management of problems associated with poor school attendance or performance (e.g. by siblings) can result in considerable cost savings – for example, involvement of an Education Welfare Officer can cost over £2,800;

- The long-term cost consequences for a child and the state of truancy and poor educational attainment can be over £50,000;

- Behavioural problems in young children can develop into challenging behaviour and anti-social behaviour, which may include criminal activity. The average cost of a crime by a young person is £4,600; annual costs for prolific offenders can exceed £50,000;

- Family breakdown increases the likelihood of educational and behavioural problems;

- Although FSWs do not give direct financial advice (e.g. on benefit entitlement), they can signpost families to agencies that can. FSWs can also help families complete the necessary forms. Disability Living Allowance can increase a family's income by over £100 per week. A Family Fund grant may enable the purchase of a much-needed item, such as a washing machine (which could cost at least £200 to purchase);

- With average gross full-time earnings being about £500 per week, and about £28,000 per year for males, providing support that enables a parent to continue in paid employment has a significant impact on household income.

E.18: These are examples of just some of the areas where considerable cost savings may result (at least in part) from the involvement of an FST. Staff at Rainbow Trust could use the costs presented in the Report (see table in Section 4 of the Report) to construct profiles for some of their families. These would help to provide a realistic picture of the extent of the savings that may be achieved, based on the experiences of real families.

E.19: In addition, the literature review stresses the importance of providing carers with short breaks from their roles to enable them to withstand the pressures and stresses that they face. Such support is valued by families and may help the family to care for the sick child at home.

E.20: The literature also shows that home-based care can often be viable and is usually less expensive than institutional-type care (although it recognises that some time in hospital may be inevitable). Additionally, it is also generally preferred by families.

Conclusion

E.21: At an average cost of about £2,500 per family (or £500 per person for a family of five), the work of the FSTs provides excellent value for money when compared with the types of costs that may otherwise have been incurred by the family or other stakeholders (such a statutory service providers) in the absence of Rainbow Trust's involvement. Such costs could easily exceed £10,000 in the short term, and be much more than this if there are long-term consequences for family cohesion, health, educational attainment and behaviour.

Acknowledgements

The researchers would like to thank Rainbow Trust, in particular the Managers of the Family Support Teams, for their contributions to this study.

Section 1: Introduction

1.1 OVERVIEW

This Report has been written by York Health Economics Consortium for Rainbow Trust Children's Charity. Rainbow Trust is a charitable organisation providing emotional and practical support for families who have a child with a life-threatening[1] or terminal illness. The Trust operates a number of Family Support Teams (FSTs) in England, each comprising a Manager and several Family Support Workers (FSWs). They offer the whole family individually tailored high quality support for as long as it is needed. This unique service is provided to the families in their homes and in the local community, and focuses on the needs of each family member, including the sick child, parents, siblings, grandparents and all extended family members.

This support includes:

- Providing emotional support to each member of the family throughout the child's illness;
- Spending time with the ill child at home or in hospital;
- Accompanying and supporting parents and their child during clinic and hospital appointments;
- Providing short breaks for the sick child and siblings, which may include fun activities at home or trips out to local amenities;
- Helping maintain normality in the home by working with, and caring for, siblings to ensure that usual activities are continued for the family;
- Providing practical support, housework, shopping etc.;
- Providing end of life care and ongoing bereavement support.[2]

Rainbow Trust is interested in exploring some of the economic and financial consequences of its work. The impacts may be felt by the families, providers of statutory services (such as the NHS and Social Services) or the wider economy (collectively referred to as 'the stakeholders'). Although it is impossible to know what would have happened to a particular family in the absence of support from Rainbow Trust, experienced Managers and FSWs can draw on their professional skills to identify what might have happened, such as the development of mental health or behavioural problems. Although working with an FSW does not guarantee that certain adverse outcomes – such as family breakdown – will not occur, it can reduce the risks of such events happening. This study draws on published literature and other studies to identify some of the cost consequences (such as the cost of having a child in foster care) that may have arisen without Rainbow Trust support. This study also includes

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[1] Life-threatening conditions are defined as those for which curative treatment may be possible but might fail, for example cancer or irreversible organ failure. Severe neurological conditions may also be deemed life-threatening once their cumulative effects cause weakness and susceptibility to major health complications.

[2] Taken from Rainbow Trust's website: www.rainbowtrust.org.uk.

estimates of some of the costs (such as the cost of transport to and from hospital and clinic appointments) that might have been incurred by the families without the involvement of an FSW.

The Report also includes a brief review of the relevant literature and analysis of the activity and cost data for the FSTs in 2009/10.

1.2 REPORT STRUCTURE

Section 2 of the Report presents the analysis of the quantitative data provided by Rainbow Trust. This covers activity and cost data from 2009/10[3], and includes the calculation of some unit costs, such as the cost per family and the cost per hour of support. It also considers how the costs are divided into 'care' and 'core' costs and how the FSW workloads are split across different types of support.

Section 3 summarised the key messages about potentially prevented expenditure (for the families and the statutory sector) drawn from telephone interviews with the Managers of the FSTs. These individuals drew upon their experiences to provide informed opinions about the value of the support provided and about what might have happened to family members without Rainbow Trust's involvement. It is important to stress that every family's situation and circumstances are different, which means that no firm conclusions can be drawn. However, similar themes and messages arose from all of the interviews, suggesting considerable uniformity in the impact of the FSTs.

Section 4 tabulates the key messages from Section 3 and the Appendix. Some of the material repeats that provided in these sections, but the section has been designed to be read on a stand-alone basis. It also includes cost material from other sources, such as health care costs and the costs of family breakdown. It therefore provides a summary of the potential costs to various stakeholders that may be saved due to input from FSTs. Some aspects can readily be identified and quantified, such as the savings for the NHS of preventing a home visit by a community nurse. Others, however, such as the financial benefits from reducing parental stress and anxiety, are more nebulous. However, failure to address these over time may result in the need to seek professional help (and possibly medication) from GPs and mental health professionals. The material in this section should therefore be seen as indicative of some of the possible financial consequences of the work of the FSTs. These consequences may be felt by a variety of stakeholders in the short term or the longer term.

Section 5 provides some concluding comments.

The Appendix presents a review of recent relevant literature about models of care for managing children with complex needs and life-limiting conditions. Prior to reading the Appendix it should be recognised that, as explained in Section 1.3, some confusion can arise over the terminology used in the literature and in 'everyday' service provision.

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[3] Rainbow Trust's financial year runs from 1 July to 30 June.

1.3 A WARNING ABOUT TERMINOLOGY

It is important that the reader of this Report understands that terminology use can differ between research publications and ‘everyday’ use. This is the case with the use of the terms ‘*respite care’* and ‘*short breaks’*. In recent years, the term ‘*short breaks’* tends to have replaced the term ‘*respite care’*. However, both of these terms are used in the published literature to describe the types of support routinely provided by the FSTs, i.e. the provision of support (which may include participating in various activities) to enable a carer (such as a parent) to have a break from caring of short periods such as hour or so, as well as for longer periods. However, many people (including professional staff) tend to use the terms ‘*respite care’* and ‘*short breaks’* to describe episodes of care when the unwell person moves into another setting for a few days to enable their carer to have a short holiday or some time to their self, or when a professional sitter goes to the unwell person’s home (for a period of an few hours to a few days) specifically to look after them so that their usual carer can go out or can go away. The terms ‘*respite care’* and ‘*short breaks’* are therefore used in the Appendix in a way that may be unfamiliar to some readers.

Section 2: Quantitative Data: Analysis of Activity and Costs

2.1 OVERVIEW

This section summarises the activity and cost data provided by Rainbow Trust. The activity data comprise information for each Family Support Team (FST) on staff numbers (including their years of experience and types of qualifications), caseload, and total hours of support. These data cover the organisation's 2009/10 financial year, which ran from 1 July 2009 to 30 June 2010. The cost data reported here are also for the same 2009/10 period, and cover actual and budgeted costs.

The quantitative analysis covers the seven Teams that were fully operational during 2009/10: County ***Durham***[4] (based in Durham and covering Northumberland, County Durham, Tyne and Wear, and Teesside)[5]; ***Cumbria*** (based in Kendal and covering Cumbria and North Lancashire); ***Manchester*** (covering Greater Manchester); ***Essex*** (based in Romford, and also covering parts of London); ***Surrey*** (based in Leatherhead and also covering Sussex, Kent and parts of London); South Central (based in ***Southampton*** and covering Hampshire, Dorset and South Wiltshire); and South West (based in ***Swindon*** and covering Swindon, North Wiltshire, Bath and North East Somerset, and South Oxfordshire). The North West London team (based in West Drayton) was not established until July 2010[6] and has therefore been excluded from the subsequent analysis.

2.2 ACTIVITY DATA

2.2.1 Staffing Levels and Characteristics

Table 2.1 shows the staffing levels of the FSTs, each of which comprise a Manager and a number of Family Support workers (FSWs). These data were provided by Rainbow Trust at the start of the project. It should, however, be noted that staffing levels are not-static, and that several of the Teams have recently appointed (or are in the process of appointing) additional staff. The table also shows the length of service of the staff. Many are very experienced and have worked for Rainbow Trust for several years.

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[4] Text in bold and italics denotes the name for the FST used in this Report.

[5] Sometimes referred to as Birtley, where it was located before moving to Durham.

[6] Some figures for Hillingdon/North West London were included in the information provided by Rainbow Trust, but these have been excluded from this analysis as the Team was not functioning fully during 2009/10.

Table 2.1: Staffing levels of the FSTs

Family support team	All staff	Family support manager	Family support workers	Length of service
Durham	6	1	5	3 months – 8 years (team total: 24 years)
Cumbria	5	1	4	2.5 years – 8 years (team total: 24 years)
Manchester	5	1	4	5 months – 5 years (team total: 9 years)
Essex	6	1	5	1 year – 10 years (average: 5 years)
Surrey	7	1	6	2 years – 13 years (average: 6.5 years)
Southampton	6	1	5	FSWs: 6 years – 14 years (average 10+ years)
Swindon	5	1	4	1 month – 2 years (average: 1 year)
TOTAL	**40**	**7**	**33**	

As well as having considerable experience of providing family support services, the staff working in the FSTs also have a wide range of qualifications. These include a variety of Certificates, Diplomas and NVQs, many of which focus on working with children. These qualifications generally have a social rather than a health focus. Some staff also have qualifications in management. Box 2.1 shows the types of qualifications held by staff working in the FSTs.

Box 2.1: Qualifications of FST staff

NNEB
NNEB in Nursery Nursing
NNEB's NVQ
Btec Childhood Studies
Btec in Social Care
Btec Diploma in Early Years
Certificate in Post Qualifying Studies
Certificate in Counselling/Counselling Skills
Certificate of Qualification in Social Work
Certificate of Higher Education in Visual Impairment
Diploma in Post Qualifying Management Studies
Diploma in Therapeutic Massage, Reflexology and Aromatherapy
Diploma in Social Work
Certificate in Management
Special Education Needs
Certificate in Palliative Care

NVQ3 in Management
NVQ3 Teachers Certificate
NVQ3 Assessors Award
NVQ3 in CCYP
NVQ3 in Health and Social Care

BA(Hons) Applied Social Studies
BSc RN Children's Nursing
Social Care Degree
Registered Nurse for Sick Children
Registered Nurse

2.2.2 Caseloads

Table 2.2 shows the caseload for each FST on 27 July 2010. It also shows the number (and their percentage) of bereaved families included in the caseloads.

Table 2.2: FST caseloads (27 July 2010)

Family support team	Caseload	Bereaved families as part of caseload (%)
Durham	95	9 (9.5%)
Cumbria	142	21 (14.8%)
Manchester	95	10 (10.5%)
Essex	73	7 (9.6%)
Surrey	98	19 (19.4%)
Southampton	118	14 (11.9%)
Swindon	43	3 (7.0%)
TOTAL	**664**	**83 (12.5%)**
AVERAGE	**95**	**12 (12.5%)**

Table 2.2 shows that the FSTs supported an average of 95 families (range: 43-142) in July 2010, including an average of 12 (range: 3-21) bereaved families. Bereaved families therefore comprised, overall, about one in eight (12.6%) of the caseload families (range: 7.0%-19.4%). There was, however, considerable variation across the FSTs.

2.2.3 Support Hours

The FSWs keep a record of their hours of work with the families, and sub-divide these hours into ‘Sibling Support’; ‘Hospital Support’; ‘Bereavement Support’; and ‘FSW Support’. ‘FSW Support’ is a generic category that encompasses all of the hours that do not fall specifically into one of the other categories (e.g. the provision of emotional support; liaising with other agencies). Although the four categories are not mutually exclusive (e.g. a hospital visit may also include sibling support and generic support), there is no double-counting of hours in the categorisation. However, some subjectivity by the FSWs in classifying their work is inevitable. Table 2.3a shows the breakdown of the hours of work for all of the FSTs, with the percentage shares presented in Table 2.3b.

Table 2.3a: Breakdown by type of hours of work by FSTs[7]

Family support team	Sibling support	Hospital support	Bereavement support	FSW support (generic)	Total
Durham	838	741	165	1,645	**3,389**
Cumbria	116	200	224	1,747	**2,287**
Manchester	304	525	23	1,973	**2,825**
Essex	139	1,241	75	1,538	**2,993**
Surrey	452	2,454	200	1,579	**4,685**
Southampton	856	1,643	94	1,818	**4,411**
Swindon	38	553	105	3,223	**3,919**
TOTAL	**2,743**	**7,357**	**886**	**13,523**	**24,509**
AVERAGE	**392**	**1,051**	**127**	**1,932**	**3,501**

Table 2.3b: Breakdown by type of hours of work by FSTs – percentage shares

Family support team	Sibling support	Hospital support	Bereavement support	Generic FSW support	Average hours support/family
Durham	24.7%	21.9%	4.9%	48.5%	35.7
Cumbria	5.1%	8.7%	9.8%	76.4%	16.1
Manchester	10.8%	18.6%	0.8%	69.8%	29.7
Essex	4.6%	41.5%	2.5%	51.4%	41.0
Surrey	9.6%	52.4%	4.3%	33.7%	47.8
Southampton	19.4%	37.2%	2.1%	41.2%	37.4
Swindon	1.0%	14.1%	2.7%	82.2%	91.1
OVERALL	**11.2%**	**30.0%**	**3.6%**	**55.2%**	**36.9**

Tables 3.3a and 3.3b show that the FSTs provided a total of about 24,500 hours of support (24,509; range: 2,287-4,685). Each FST therefore provided an average of about 3,500 hours of work (3,501) over the year, giving an average of approximately 37 hours per family (36.9; range: 16.1-91.1). The majority of hours were spent providing generic FSW support, which accounted overall for over half of the hours worked (55.2%; range: 33.7%-82.2%). Hospital support was the next largest category, accounting for an average of almost one-third of the hours (30.0%; range: 8.7%-52.4%). Sibling support[8] accounted, on average, for slightly more than 10% of FST time (11.2%; range: 1.0%-19.4%). Overall, less that 5% of FST time was spent giving bereavement support (3.6%; range: 0.8%-9.8%). Several factors (e.g. local geography; numbers, locations and proximity of hospitals treating very sick children; balance between hospital-based and community-based provision) will be responsible for these variations between the FSTs.

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[7] Slight discrepancies were found in the data on support hours provided by Rainbow Trust for four of the FSTs. For these FSTs, the sum of the hours given for sibling support, hospital support, bereavement support and FSW support was less than the total number of hours provided for the FST. In these situations, the difference between these totals was pro-rated across the four categories to ensure that their total was the same as the overall stated total for the FST.

[8] This includes support to the wider family (e.g. grandparents).

2.3 COST DATA

2.3.1 Actual Costs and Percentage Shares

Rainbow Trust provided copies of the accounts for the FSTs during their 2009/2010 financial year. The actual costs are split into two broad categories – *care costs* and *core costs*. The care costs are further sub-divided into three broad groups – 'people costs'; 'establishment costs'; and 'travel and motor'. The core costs cover the Teams' share of Rainbow Trust's central overheads[9].

Table 2.4a shows the actual costs during 2009/10 for these categories, with the percentage shares being shown in Table 2.4b.

Table 2.4a: FST costs – 2009/10

Family support team	People costs	Establish-ment costs	Travel and motor	Total care costs	Core costs	Grand total
Durham	£107,965	£4,153	£27,999	**£140,117**	£64,180	**£204,297**
Cumbria	£108,982	£11,691	£29,980	**£150,653**	£64,180	**£214,833**
Manchester	£97,350	£7,670	£24,128	**£129,148**	£64,180	**£193,328**
Essex	£120,221	£9,898	£44,996	**£175,115**	£83,982	**£259,097**
Surrey	£166,929	£16,114	£41,558	**£224,601**	£100,353	**£324,954**
Southampton	£136,052	£12,543	£38,656	**£187,251**	£89,745	**£276,996**
Swindon	£85,718	£8,042	£21,411	**£115,171**	£59,830	**£175,001**
TOTAL	**£823,217**	**£70,111**	**£228,728**	**£1,122,056**	**£526,450**	**£1,648,506**
AVERAGE	**£117,602**	**£10,016**	**£32,675**	**£160,294**	**£75,207**	**£235,501**
Average Cost per FST Worker (40)	**£20,580**	**£1,753**	**£5,718**	**£28,051**	**£13,161**	**£41,213**

Table 2.4b: Percentage shares of care costs and core costs for FSTs – 2009/10

Family support team	People costs as % total care costs	Establishment costs as % total care costs	Travel and motor as % total care costs
Durham	77.1%	3.0%	20.0%
Cumbria	72.3%	7.8%	19.9%
Manchester	75.4%	5.9%	18.7%
Essex	68.7%	5.7%	25.7%
Surrey	74.3%	7.2%	18.5%
Southampton	72.7%	6.7%	20.6%
Swindon	74.4%	7.0%	18.6%
OVERALL	**73.4%**	**6.2%**	**20.4%**

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[9] These were Design and Brand; PR; Care Manager South; Director of Care; HR; and Central Overheads. Since then, the post of Care Manager South has been replaced by two Heads of Care in the central overheads/core costs.

Table 2.4a shows that a total of £1.12 million was spent on care costs in 2009/10, rising to almost £1.65 million when the core costs are also taken into account. Core costs were about £0.53 million. Almost three-quarters of the care costs (73.4%; range: 68.7%-77.1%) cover people costs (mainly salaries). About one-fifth (20.4%; range: 18.5%-25.7%) are absorbed by travel and motor costs, with the remainder (6.2%; range: 3.0%-7.8%) being accounted for by establishment costs (e.g. rent; phones; office equipment).

The average total care cost per FST was £160,294, comprising averages per FST of £117,602 (73.4%) for people costs, £32,675 (20.4%) for travel and motor, and £10,016 (6.2%) for establishment costs. Core costs averaged £75,207 per FST, giving an average total cost for each FST of £235,501. The average total care cost per FST staff member was £28,051, comprising £20,580 for people costs, £5,718 for travel and motor, and £1,753 for establishment costs. When the core costs are included, the average total cost per FST staff member was £41,213.

Table 2.5 shows that, overall, total costs comprise about two-thirds care costs (68.1%; range: 65.8%-70.1%) and one-third core costs (31.9%; range: 29.9%-34.1%). People costs account for about half of the total costs (49.6%; range: 45.4%-52.8%).

Table 2.5: Percentage shares of cost components

Family support team	People costs as % grand total	Establishment costs as % grand total	Travel and motor as % grand total	Care costs as % grand total	Core costs as % grand total
Durham	52.8%	2.0%	13.7%	**68.6%**	**31.4%**
Cumbria	50.7%	5.4%	14.0%	**70.1%**	**29.9%**
Manchester	50.4%	4.0%	12.5%	**66.8%**	**33.2%**
Essex	45.4%	3.7%	17.0%	**67.6%**	**32.4%**
Surrey	50.7%	4.9%	12.6%	**69.1%**	**30.9%**
Southampton	49.1%	4.5%	14.0%	**67.6%**	**32.4%**
Swindon	49.0%	4.6%	12.2%	**65.8%**	**34.1%**
OVERALL	**49.6%**	**4.2%**	**13.8%**	**68.1%**	**31.9%**

2.3.2 Differences between Actual and Budgeted Costs

Table 2.6 shows that, overall, actual expenditure on the FSTs (£1,648,506) was slightly less than £67,000 (£66,830) below the budgeted amount (£1,715,336). This meant that actual expenditure was almost 4% less than the budgeted amount (3.9% below; range: 10.0% above to 15.1% below). However, there was considerable variation between the FSTs with regard to differences between their actual expenditure in 2009/10 and their budgets. Expenditure by five of the FSTs was below budget whilst it was over budget for two of the FSTs.

Table 2.6: Actual and budgeted costs for FSTs – 2009/10

Family support team	Actual	Budget	Actual - budget	% variance (actual>budget)
Durham	£204,297	£193,745	£10,552	**5.4%**
Cumbria	£214,833	£195,243	£19,590	**10.0%**
Manchester	£193,328	£227,746	-£34,418	**-15.1%**
Essex	£259,097	£281,703	-£22,606	**-8.0%**
Surrey	£324,954	£341,767	-£16,813	**-4.9%**
Southampton	£276,996	£289,651	-£12,655	**-4.4%**
Swindon	£175,001	£185,481	-£10,480	**-5.7%**
OVERALL	**£1,648,506**	**£1,715,336**	**-£66,830**	**-3.9%**

2.3.3 Unit Costs: Actual and Average Costs per Family

The following three tables present some unit costs for the FSTs. Table 2.7 shows that the *average care cost per family* was almost £1,700 (£1,690; range: £1,061-£2,678). This unit cost was therefore about two-and-a-half times higher in the most costly FST than in the least costly one. The *average care cost per support hour* was £46 (range: £29-£66). When the core costs are also included, the *average total cost per family* was almost £2,500 (£2,483; range: £1,513-£4,070). The *average total cost per support hour* was £67 (range: £45-£94).

Table 2.7: Unit costs (care costs and total costs) per family and per support hour

Family support team	Average care cost per family	Average care cost per support hour	Average total cost per family	Average total cost per support hour
Durham	£1,475	£41	£2,150	£60
Cumbria	£1,061	£66	£1,513	£94
Manchester	£1,359	£46	£2,035	£68
Essex	£2,399	£59	£3,549	£87
Surrey	£2,292	£48	£3,316	£69
Southampton	£1,587	£42	£2,347	£63
Swindon	£2,678	£29	£4,070	£45
Overall Average[10]	**£1,690**	**£46**	**£2,483**	**£67**

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[10] Overall Averages are calculated from the aggregate values across the FSTs. They are not an average of the average values for each FST.

There are many possible explanations of the differences between the FSTs. It is suggested that managerial staff at Rainbow Trust discuss these differences with the FSTs to determine if any lessons can be learned to improve service efficiency. However, the differences may be for valid reasons, such as:

- Differences in FST budgets and expenditure;
- Numbers of staff in FST (this may influence the extent to which the Teams can achieve economies of scale);
- Size of FST caseload;
- Maturity of FST (relatively new Teams may still be experiencing set-up costs);
- Office-related costs (e.g. local rents; provision of rent-free accommodation);
- Staff salary levels (e.g. use of staff on secondment; seniority of staff);
- Locations of hospitals used by families and distances travelled;
- Size of area covered by FST;
- Different ways of working across the FSTs (e.g. allocation of families across FSWs);
- Different ways of coding types of hours by the Teams.

Tables 2.8a and 2.8b show the average care costs and the average total costs of the various types of support provided by the FSTs. Table 2.7 showed that the average care cost per family was £1,690. Table 2.8a shows that this comprises an average per family of £189 for sibling support (11.2%), £507 for hospital support (30.0%), £61 for bereavement support (3.6%), and £932 for generic FSW support (55.2%). As above, however, there is considerable variation between the FSTs.

Table 2.8a: Unit costs of categories of care costs per family

Family support team	**Average care cost of sibling support per family**	**Average care cost of hospital support per family**	**Average care cost of bereavement support per family**	**Average care cost of generic FSW support per family**
Durham	£365	£322	£72	£716
Cumbria	£54	£93	£104	£810
Manchester	£146	£253	£11	£949
Essex	£111	£995	£60	£1,233
Surrey	£221	£1,200	£98	£772
Southampton	£308	£591	£34	£654
Swindon	£26	£378	£72	£2,203
Overall Average	**£189**	**£507**	**£61**	**£932**

Table 2.7 also showed that the average total cost per family was £2,483. Table 2.8b shows that, when core costs are included in the totals, the average total cost of sibling support per family was £278, with £745 for hospital support, £90 per bereavement support, and £1,370 for generic FSW support. The percentage breakdowns are as stated above for Table 2.8a.

Table 2.8b: Unit costs of categories of total costs per family

Family support team	**Average total cost of sibling support per family**	**Average total cost of hospital support per family**	**Average total cost of bereavement support per family**	**Average total cost of generic FSW support per family**
Durham	£532	£470	£105	£1,044
Cumbria	£77	£132	£148	£1,156
Manchester	£219	£378	£17	£1,421
Essex	£165	£1,472	£89	£1,824
Surrey	£320	£1,737	£142	£1,118
Southampton	£456	£874	£50	£967
Swindon	£39	£574	£109	£3,370
Overall Average	**£278**	**£745**	**£90**	**£1,370**

2.4 SUMMARY

The above tables have summarised the analysis of the activity and cost data for the FSTs in 2009/10. They have shown that:

- The average caseload per FST was 95 families, with a range of 43 to 142;
- The average number of bereaved families in the caseloads was 12 (i.e. about one in eight, or 12.5%), with a range of 3 to 21 (7.0%-19.4%);
- The FSTs spent an average of 36.9 hours with each family (range: 16.1–91.1) during the year;
- The FSTs provided a total of 24,509 hours of work (with an average of 3,501 per FST);
- The FSTs spent this time providing four main types of support:
    - Generic support: 55.2%;
    - Hospital support: 30.0%;
    - Sibling support: 11.2%;
    - Bereavement support: 3.6%.
- The FSTs cost a total of almost £1.65 million (£1,648,506), of which £1.12 million (£1,122,056) was for care costs and £0.53 million (£526,450) was for core (central overhead) costs;
- 73.4% of the care costs were for people costs (i.e. staff-related), 20.4% for travel and motor costs, and 6.2% for establishment costs;

- Core costs accounted for almost one-third (31.9%) of total costs, with care costs accounting for the other two-thirds (68.1%);
- People costs therefore accounted for almost half (49.6%) of total costs;
- The overall budget for 2009/10 (£1,715,336) exceeded actual expenditure (£1,648,506) by almost £67,000 (3.9%), although there was considerable variation between the FSTs (ranging from a 10.0% overspend to a 15.1% underspend).

Table 2.9: Summary of the key unit costs

Unit Cost	Average for All FSTs	Range Across FSTs
Average care cost per family	£1,690	£1,061 - £2,678
Average care cost per support hour	£46	£29 - £66
Average total cost per family	£2,483	£1,513 - £4,070
Average total cost per support hour	£67	£45 - £94
Average total cost of generic FSW support per family	£1,370	£967 - £3,370
Average cost of hospital support per family	£745	£132 - £1,737
Average total cost of sibling support per family	£278	£77 - £532
Average total cost of bereavement support per family	£90	£17 - £148

Section 3: Qualitative Data: Interviews with Family Support Team Managers

3.1 INTRODUCTION

As part of this research telephone interviews were undertaken with the Managers of the Family Support Teams (FSTs). These semi-structured interviews generally lasted for about 30 to 45 minutes and explored several features of the work of the FSTs. In particular, the Managers were asked to identify the aspects of the work of their Teams (and of the approach adopted by Rainbow Trust) of which they were the most proud and which they felt had the greatest impact on all family members.

Although recognising that it is impossible to know what would have happened to the members of a family in the absence of support from Rainbow Trust, Managers were asked to use their professional opinion and experience to speculate on what may otherwise have occurred, and the possible financial impacts on the families and/or on other services. This information was subsequently used by the researchers (see Section 4) to inform their estimates of the potential cost consequences of the work of the FSTs (e.g. preventing the need for expenditure by the various stakeholders), and thus the value added by them.

When considering the cost consequences of any intervention, it is important to recognise that these have several dimensions. One important dimension is the time scale of the benefit/saving; many may be immediate or in the short term (e.g. that day, month or year), whereas some may be relevant in the longer term (e.g. several years later; over a lifetime). Another important aspect is the stakeholder that benefits financially. This may be the family, the health and social care sector (both statutory and voluntary elements), or the wider Exchequer[11]. Although the magnitude of the financial and economic benefits can be hard to quantify, it is clear that all families will benefit (to a greater or lesser extent) from the support provided by the FSTs.

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[11] For example, providing transport to a hospital appointment has immediate financial benefits for the family. Reducing the likelihood of adults or children developing mental health problems has significant long-term financial consequences for the individuals and for health and social care services (as well as short-term benefits). Enabling an adult to continue in employment has benefits to the person (their wages/salary) and the exchequer (increased tax revenue and decreased benefit payments).

3.2 TEAM CHARACTERISTICS

Rainbow Trust operates strict acceptance criteria for families – a child has to have a life-threatening condition or a terminal illness. Contact can last from a few weeks to several years, and may sometimes be intermittent, depending on the family's needs. As shown in the tables in Section 2, the FSTs vary in size, and their staff have a wide variety of backgrounds, skills and qualifications. It is important that they have 'life experience' and are sufficiently mature to handle the emotional aspects of the work. The FSTs hold regular round-table staff meetings to discuss their work and any particular challenges. Staff also have access to support from Rainbow Trust, if necessary, to help them to cope with the pressures they face. They need to be sympathetic and caring, but also need to be able to set and maintain professional boundaries with their families. In addition, they need to work well with staff from other organisations from the statutory and voluntary sectors.

The size of the caseload of each FST and of each member within it varies (between about 20 and 30 families per FSW). Some families will be visited on a regular basis (e.g. weekly; fortnightly), whereas others are seen on more of an *ad hoc* basis, as determined by their changing needs. All FST staff are provided with a lease car (for which they pay private mileage) and a mobile phone. They also have access to a pool of child seats.

3.3 TYPES OF WORK

FSTs provide a variety of types of support to their families. They classify their contact with families as 'generic FSW support'; 'hospital support'; 'sibling support'; and 'bereavement support'. Work may be with the sick child, the parents, any siblings, or members of the wider family (e.g. grandparents). Time spent with a specific family member can have wider benefits – for example, taking a sibling to the park can also provide the parents with a short break (or period of respite). There is therefore some overlap between the types of support.

3.4 GENERIC FSW SUPPORT

3.4.1 Broad Characteristics

The FST Managers were asked to identify the key features of the work of the FSTs, and how this differs from other services. The following characteristics were frequently mentioned:

- Work with the whole family;
- Holistic care and an holistic approach;
- Vital to build up trust;
- Tailor-made support;
- Flexible – support changes as family needs change;
- Family-led (rather than directed by the referrer);
- Provide emotional and practical support;

- Responsive;
- Not time-specific or time-limited;
- Can prevent problems from developing;
- Can signpost to appropriate agencies where necessary;
- Provide continuity over a period of time (during which a family may come into contact with many different people from other agencies).

Another key feature is that the FSTs are seen by the families as being non-threatening and non-judgemental – staff from some statutory services can be perceived by families as being ‘preachy’ or ‘condescending’. The FSWs see the family in a wide variety of situations, including in their homes (‘when their guard may be down’; ‘in their raw state’). Other professionals may only see the child and the parents in a formal setting, and may be unaware of any other family members also affected by the child’s illness or of stresses being faced by the family (e.g. relating to housing). Many families are worried about cutbacks in other services, and appreciate that Rainbow Trust ‘is just there’.

Families with a very sick child are in an unfamiliar situation that they do not want to be in, and feel under pressure all of the time. All families have different ways of coping, and the FSWs can help them with these. The FSWs can ‘help families survive hell’ and make their situation less unbearable. Being able to contact Rainbow Trust at any time (i.e. 24/7) is greatly appreciated by the families, especially if they are experiencing a crisis.

Some parents are very young. Some are single mothers, often without other family or friends. Many families live in totally unsuitable accommodation. There can be feelings of guilt in some families, especially if the condition is genetic (such as a chromosomal abnormality). Several of the Managers commented that the FSWs ‘put a smile on the children’s faces’ (for the sick child and their siblings), and that ‘their faces light up when they see the FSW’. Other family members are also often very pleased to see their FSW.

3.4.2 Support for Sick Child

The FSWs can support the sick child in many ways, including visiting them in hospital and providing transport to appointments and, if relevant, school (or nursery or playgroup). They can sit with the child (either at home or in hospital), listen to them and play with them, and they provide the child with another trusted person they can turn to and rely on. Sometimes the sick child will discuss things with their FSW that they do not want to talk about with family members.

Some FSWs (after relevant training) will undertake limited invasive procedures, such as artificial feeding either by nasogastric tube or gastrostomy tube or suction. As well as preventing the need for a home visit by a community-based nurse, this can also help the mother-child relationship. The FSWs may also enable a sick child with special requirements (e.g. being on oxygen or requiring suctioning) to attend a playgroup, nursery or school, thus letting them enjoy some ‘normality’ and social contact with peers. Attending such activities can provide variety and stimulation for the sick child. Sitting with the child or enabling them to attend activities outside the home can also provide a much-needed break from caring for the mother, who can focus for a while on her needs or those of other family members.

3.4.3 Support for the Family

The FSWs provide wide-ranging support to all members of the family, including grandparents if appropriate. Such support can be emotional or practical. Some parents have relatively weak parenting skills (e.g. providing an appropriate diet; maintaining routines and discipline), and may require help with these. For example, a child on steroids can have a ferocious appetite, and the parents may need help with planning suitable meals for all the family. Many parents also have relatively poor reading and numeracy skills and appreciate help with understanding written information and form filling. Some parents have difficulty grasping the seriousness of their child's illness and the importance of complying with instructions (e.g. regarding medication). Even parents who are well organised can struggle with managing the competing and relentless pressures that they face and may find, especially over time, that they cannot rely on other family members, friends and neighbours to help out (e.g. with looking after siblings after school to enable hospital visits by the parents).

Parents, siblings and other family members appreciate being able to talk about their stresses, problems and fears with an understanding person who is not a family member – FSWs need to be good listeners. Some parents are also caring for their own parents, which further increases the pressures that they face.

Although Rainbow Trust no longer provide holiday facilities for families[12], some Managers have good links with local hotels/guest houses that specialise in providing holidays and breaks for families with a disabled child. Such holidays can be of great benefit to all of the family members.

It is often important to try to keep families together and prevent family breakdown. This may not always be possible and some relationships may have been in serious difficulty before the child's diagnosis. Sometimes staying together is not the best outcome, especially if domestic violence and/or abuse (of the partner and/or of children) are being experienced, or are at risk of happening. However, some relationships deteriorate because the parents have different ways of coping with the pressures being experienced by the family, and communication and understanding between them can often break down. As one Manager described it, an FSW can "*help her to keep together, help him to keep together, and help both of them to stay together*". Some fathers 'go very quiet' or 'get very escapist' and then 'just fade away', leaving the mother to cope with everything as a single mother. This may result in the child or siblings having to be placed in foster care, and the Managers described examples of families where the FSWs had helped to keep them together and prevent one or more children going into care. Taking a longer-term perspective, much research has been undertaken that shows that the risks of children from broken homes developing social and behavioural problems are much greater than for children from stable homes. Social and behavioural problems can affect their educational achievements and may also lead to anti-

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[12] This was due to a strategic change of direction by Rainbow Trust, who decided to increase their community support by creating a new FST and recruiting additional FSWs to existing Teams.

social and criminal behaviour, which adversely affect their life chances. The costs of family breakdown for public services and society can be very high.

Also, families often need support to help them stay together after the death of a child as they struggle to re-establish ‘normality’ in their family lives. The FSW cannot always prevent relationship breakdown, but they may be able to help parents stay together for longer than they otherwise would have done, which may be of benefit to the sick child and the siblings.

3.4.4 Facilitation and Advocacy

Families can often feel powerless and may have no idea where to turn for help. The FSWs can often signpost families to the appropriate services, or put them in contact with relevant professionals. They can also attend meetings between the family and other agencies to provide some advocacy and support. In addition, the FSWs can often see social and other problems developing within a family, and can contact other professionals and instigate meetings to try to prevent such problems from escalating. They sometimes attend multidisciplinary team (MDT) meetings with the family, who may otherwise find such events totally overwhelming. The following two paragraphs – on financial support and on housing and education – provide examples of the facilitation and advocacy work of the FSWs.

3.4.5 Financial Support

As shown in the literature review in Section 2, families caring for a sick child face enormous financial pressures on top of all of the emotional stresses and practical difficulties. The telephone interviews revealed that the FSWs are not responsible for informing families about the financial support and other benefits for which they may be eligible (such as Disability Living Allowance), although they can signpost them to an appropriate agency or professional, if necessary. However, they often help families fill out the necessary forms, which can be quite daunting and complex. FSWs can also help a family identify and assemble the information they will need for a meeting with, for example, a housing officer to discuss ways of meeting rent payments or arrears.

Many families where one or both parents had been in employment face a significant drop in household income after the sick child has been diagnosed. Some employers are more accommodating than others with regard to time off work (paid or unpaid). Annual leave entitlements can quickly be absorbed by hospital appointments. Overtime opportunities may be greatly curtailed, and parents who are self-employed will have less access to sick pay or compassionate leave that those who are employees (though they may have more flexibility around their hours of work than some employed people). Pressure to take time off work for hospital appointments or managing the household (e.g. meeting siblings’ needs) can be reduced when the FSW is able to perform some of the tasks that would otherwise have had to be undertaken by a parent. Nevertheless, many families are likely to acquire debts due to their increased financial pressures and their decreased income from employment.

FSWs may also be able to help eligible families apply for financial help from the Family Fund. This organisation provides grants to help ease the pressures faced by families caring for a disabled child by providing help with purchasing essential items such as washing machines and tumble driers, fridges and freezers, and clothing. It will also consider grants for sensory toys, computers and much-needed family breaks.

3.4.6 Help with Housing and Education

The FSTs try not to get directly involved in housing issues, though they can signpost families to appropriate agencies. However, some families are in totally unsuitable accommodation, and many of them face very long waits for essential adaptations. Many areas have extreme shortages of social housing, resulting in few, if any, alternatives. The private rented market can often be prohibitively expensive for families with a disabled child.

The FSWs can help with education-related issues in a number of ways. Some sick children will be able to attend a playgroup, nursery or school with some additional support, such as help with oxygen or suctioning. In some circumstances the FSWs can educate staff at the facility to cope with the necessary procedures. They can also help transport the sick child (who may have a wheelchair) to and from school and may even help them move around within the school. The FSWs are often involved in transporting siblings to and from school and other activities. In addition, they may go to school meetings that the parents are unable to attend. Such support helps the children partake in 'normal' activities and ensures that their education is affected as little as possible.

3.4.7 End-of-Life Support

This is also discussed further under 'bereavement support' (Section 3.7). Where appropriate, FSWs can help to enable a child to die in the family home rather than in hospital or a hospice. Hospital-based or community-based staff may not automatically discuss such possibilities with the parents, but the FSWs can make parents aware of the options. The child will need to be nursed in the home by appropriately-trained community-based nurses, but the parents may be reluctant to agree to this unless they are confident about the care and the necessary procedures. The FSWs cannot provide any of the clinical care but, through their experience of other deaths at home, they can (if wished) facilitate the process and provide the necessary reassurance and support to the family. The FSWs sometimes work in pairs in such situations so that they can provide intensive emotional and practical support to the family throughout this period.

Although there are no specific cost figures for this, death in the home is likely to be less expensive than death in a hospital or hospice. The family may also find it less traumatic if their child dies in familiar, homely surroundings.

3.5 HOSPITAL SUPPORT

Rainbow Trust is not a hospital transport scheme, but many families struggle with transport to hospitals, clinics and surgeries. Offering help with transport is often the starting point for working with a family, and enables trust to develop between the family and the FSW. Helping with transport provides reassurance and is convenient, quicker and cheaper than the alternatives (which include public transport, friends/relatives, taxis, and hospital transport). Cross-infection may be a risk with some of the alternative forms of transport, and cars will need to be fitted with appropriate child seats.

Travelling to hospitals and other related settings with a sick child and their siblings can be very problematic and expensive. In some rural areas there may be very few feasible options. Providing transport can help to ensure that clinics and appointments are attended and medication collected. The FSW cars have child seats and plenty of space for luggage and equipment. Furthermore, car journeys with the FSW provide good opportunities to build relationships and provide emotional support (which may be easier if people are sitting side-by-side rather than opposite each other).

Hospital support is not restricted to providing transport and taking the sick child to appointments. Some sick children are in hospital for long periods of time (possibly for several months) and the FSWs can help take the parent(s) and other family members to visit the child there. Some mothers are very reluctant to leave their child’s bedside, but the FSW can sit with the child instead, enabling the mother to have a short break, get something to eat and drink, or talk privately with medical staff. She may wish to go home for a while and spend some time with other family members, such as siblings, or to catch up with shopping and other chores. She will be more prepared to do this if she is confident that her child will be attended by, and cared for, by a trusted person during her absence. Additionally, the child often appreciates seeing a different but familiar face for a while. Many FSWs can engage the child in therapeutic play or help with their education, if appropriate. The FSWs are often well-known by staff working on the children’s wards in their local and specialist hospitals.

In addition, the FSW can accompany the family to clinics and appointments if requested. They can help the family understand what may be complex medical terminology and jargon. They can help prevent misunderstandings and can clarify any uncertainly about information and treatment. They can also provide reassurance and support in difficult and stressful situations. They can also look after any siblings who have also had to come to the hospital.

The FSWs can also provide transport in various other situations, such as taking a child or sibling to and from school (or a nursery or a playgroup) and other activities. This will enable the sick child and/or their siblings to engage in ‘normal’ day-to-day activities with their friends and peers, which may prevent social isolation and associated problems.

3.6 SIBLING SUPPORT

Most services (and resources) will focus on the sick child and possibly also on their parents. Rainbow Trust recognises that the needs of other family members (especially siblings, but also grandparents) are also very important. These needs may be emotional and/or practical, although some siblings (especially older ones) may be reluctant to engage with the FSW (at least initially).

Siblings can experience a wide range of feelings and emotions – they may feel ignored and left out, frightened, confused, helpless or resentful. These feelings can be manifested in many ways - the child may become withdrawn or badly behaved. Depending on their age, they may start bed-wetting or being disruptive or truanting at school (some schools appear to be very supportive of a pupil with a very sick sibling, but this is not always the case). Over time 'bad' behaviour can become anti-social and challenging. A withdrawn child may develop mental health problems and become socially isolated.

FSWs can provide 'special time' with a sibling – for example they can take them on outings and make them feel important and valued. They can listen to siblings' concerns and provide reassurance. They can 'put a smile on their faces' and 'give them some fun'. They can collect them from school and take them to other activities. This can provide the parents with a short break and a bit of relief, or enable them to visit the sick child in hospital. The FSWs may take them to school to ensure that they are not late. They can look after siblings (either in the family home or at the hospital) during hospital visits or appointments. If they are in the family home they can bath them and put them to bed while the parents are out at the hospital. Sometimes they may look after all of the children so the parents can have an evening out and some time together. They can attend school meetings and functions on behalf of the parents.

The FST Managers gave examples where they felt that their involvement had prevented a sibling being placed in care because the parents were unable to cope anymore and felt that they could no longer rely on help from other family members or neighbours. Although a spell in foster care is not always a negative experience (and indeed some children may benefit from being in such an environment), the importance of keeping families together wherever possible is generally well recognised. For some families this is facilitated by the support provided by the FSW. Furthermore, FSW time spent exclusively with siblings may reduce the likelihood of other serious problems developing.

3.7 BEREAVEMENT SUPPORT

There is not a linear path from diagnosis through treatment to bereavement, and it is important to recognise this. Everyone reacts and copes in different ways, which can cause tensions and misunderstandings within families. For many families, their grieving and bereavement start at diagnosis, after which their lives and that of the sick child will never be the same again. Some parents, however, are in denial from the outset. The FSWs are not trained bereavement councillors, though they can signpost families to specialist services if appropriate. Many families, however, prefer the informal support provided by a trusted person who knows the family well (such as an FSW). The FSWs can also often provide a sympathetic ear for the sick child (who may not want to discuss their fears with a parent, so as not to upset them). Siblings can also appreciate being able to talk about their feelings with a trusted and familiar adult. Some families can find making memory boxes very helpful, and FSWs can help with these.

Most families have no experience of a child dying at home – indeed, they may not even be aware that this may be an option. FSWs can help a family be aware of the possibilities, especially if the child has been in hospital for a long time. Hospital-based medical teams often seem to be unaware of feasible alternatives, such as a children’s hospice or the family home. Place of death can have a profound effect on the coping abilities of family members both during and after the child’s death.

After the death of a sick child a family often has to rediscover itself and redefine ’normality’. This period of adjustment can be very stressful, increasing the risks of health problems (mental and physical), relationship breakdown, and behavioural issues. A break - such a short holiday together - can be helpful for a bereaved family.

The FSWs can provide as much or as little bereavement support as the family wants, for as long as it is needed. This support may be on an intermittent basis, but being able to contact a known and trusted person, if necessary, can be very reassuring for a family.

Section 4: Economic Impact of the Family Support Teams

4.1 OVERVIEW

This section tabulates the benefits provided by the FSTs and provides estimates (mainly from published research) of the likely economic impacts on the families, key service providers, and the wider Exchequer. The material is drawn from a variety of sources, including Section 3, the Appendix and other relevant publications.

Intervention	**Main Benefits**	**Other Relevant Points**	**Financial Consequences**	**Financial Beneficiaries**	**Source of Cost Data**
ASSISTANCE WITH TRAVEL					
Travel to hospital appointments	Saves costs of using own private transport	Dependent on distance travelled, hospital parking costs and type of vehicle – wide range of possible savings	• Possible savings approx. £5-£30 per journey, depending on distance travelled (estimate) • Estimated costs of £325 for travel and parking for a cancer patient making an average of 53 trips (2004 prices)	Family	Costs for cancer patient from Macmillan Cancer Support, 2006
	Prevents need to hire a taxi	Depends on distances and local hire charges – wide variations likely. Need two journeys. Need appropriate child seat(s)	Approx. £5-£30 per journey (estimate)	Family	
	Prevents using public transport	Can be very unpredictable and infrequent. Possible risk of cross-infection. Costs depend on number of people travelling, type of transport and distance	Approx. £1-£10 per person per journey (estimate)	Family, and NHS if cross-infection prevented	
	Prevents using outpatient Patient Transport Service arranged by the hospital/NHS	May involve long waits and long journeys (e.g. if shared patient transport service (PTS) journey). Risk of cross-infection	May not be a charge to the users. National average unit cost to NHS of £29 per PTS journey	NHS (for transport and possibly due to prevention of infection)	NHS Reference Costs 2008/09
	Prevents using community/volunteer transport	May need two journeys. Need appropriate car seat(s)	May charge users ~40p/mile. Approx. £5-£40 per journey (estimate)	Family	
	Convenience – reduces worry and stress about travelling and parking	May reduce visits to GP and use of medication	See later		
Travel to hospital visits (child as inpatient)	Prevents need for family to use other private or public transport	See above. Parking may be considerably more expensive if long hospital visits (though may be reclaimable from hospital)		Family	

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
Travel to other appointments (e.g. GP; community clinic)	Prevents need to walk, take a taxi or use other private/public transport	See above for travel to hospital appointments. Journeys likely to be shorter and may not have to pay for parking		Family	
ATTENDING VARIOUS APPOINTMENTS					
Provide support and reassurance to parents and child	May reduce stress felt by parent(s) and child				
Hear information and instructions and help parents recall and understand it	Another person (with less personal involvement) to listen to and remember information, advice and instructions given by clinical and other staff (e.g. social workers). May also be more likely to ask questions and seek clarification if necessary	May reduce misunderstanding and prevent inappropriate actions (e.g. with regard to giving medication) and their adverse consequences			
SUPPORT FOR SICK CHILD					
Sit at hospital bedside to provide brief respite for parent(s); can also provide similar support within the home	Enables parent(s) to have a short break and get something to eat/drink and/or buy some provisions in the hospital	Parents can be at their child's hospital bedside for days at a time; it is important they look after their own needs/health			
	Enables parent(s) to leave hospital grounds to get something to eat/drink and/or visit local shops/stores for provisions	Items may be cheaper away from the hospital concourse – also often more choice at local shops. Exercise is important for personal wellbeing	May be able to save £5-£10 per day (estimate) if shop for food, drink and provisions at local shops rather than in hospital facilities	Family	

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
Play with child (at home or in hospital); possibly help child with studies	Use training and skills to engage in appropriate play activities or other activities	Some hospitals do not have play staff. FSW able to give child undivided attention and help their general wellbeing (and possibly to maintain their education)			
Undertake certain (restricted) medical tasks and clinical interventions (e.g. injections; taking blood) in the child's home	Prevents need for home visit by Nurse (e.g. Community Nurse, District Nurse, Health Visitor) to undertake the task(s) and may also prevent need to take child to a community-based clinic	May reduce stress on parent(s) (and possibly the child) if a parent would otherwise have undertaken the activity	• Preventing the cost of a home visit by a Nurse: £26 per home visit by Community Nurse; £39 per home visit by Health Visitor • £90 national average unit cost of community nursing services for children	NHS	PSSRU, 2008 edition; NHS Reference Costs, 2008/09 (NHS Trusts Community Nursing Services for Children)
Advise parent(s) about appropriate diet (e.g. steroids can give children a ferocious appetite) - and possibly advise on other parenting skills	Eating an appropriate diet should help promote the child's general wellbeing (and possibly that of other family members)		May be some small savings if family eat a healthy diet (e.g. do not rely solely on takeaways)	Family	
Help child access education (playgroup/ nursery/ school)	Provide transport and/or attend with child (e.g. to manage medical equipment; push wheelchair)	Enables child to engage in 'normal' activities with peers and to maintain their studies with others in their age group. Helps to promote wellbeing (physical and/or mental) and reduce social isolation. Can provide parent(s) with a much-needed break. Maintaining education may also be important for longer-term earning capacity (which could reduce reliance on state benefits in adulthood)		Child/Family	

Intervention	**Main Benefits**	**Other Relevant Points**	**Financial Consequences**	**Financial Beneficiaries**	**Source of Cost Data**
Help child access other social and leisure activities	Provide transport and/or attend with child (as above)	Enables child to make friends and develop hobbies and interests. Helps to promote wellbeing and reduce social isolation. Provides break for parent(s)			
Provision of 24/7 Help Line by Rainbow Trust	Reassurance for families that they can contact someone at Rainbow Trust at any time, who will respond appropriately	Helps to prevent parental stress, especially at time of crisis			
Transition support	Moving from children's services to adult services can be very traumatic for the child and their family. The FSW can provide an element of continuity at this difficult time	This was not mentioned by any of the FST Managers, but could be provided if required			
SIBLING SUPPORT					
Give siblings individual time and attention to prevent them from feeling jealous, ignored or resentful	Either in the home or by taking them on trips/outings. May include taking care of them when parent(s) make hospital visits.	May reduce the risk of developing mental health problems and the need for input from child & adolescent psychiatry. Waiting times for CAMH services can be very long.	• £274 – national average unit cost for face-to-face meeting with Mental Health Specialist Team (non-specific reason). Ten sessions would therefore cost £2,740. • £436 - national average unit cost of first outpatient mental health consultant appointment (£257 for follow-up appointments)	NHS	NHS Reference Costs for NHS Trusts, 2008/09

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
		May also reduce the risk of behavioural problems developing, which in turn may lead to challenging behaviour or anti-social behaviour (ASB). ASB may be particularly problematic during adolescence, but inappropriate behaviour can start at a much younger age.	The potential costs associated with crime and criminal justice are considerable, both in the short-term and the longer-term. For example: • £4,125 domestic burglary • £5,250 for car theft • £6,462 for graffiti • £4,600 average cost per crime by young person • £6,260 average cost of crime by person on Supervision Order • £55,000-£100,000 per year for place in Young Offenders Institution • £24,000-£80,000 per year offending and ASB costs for prolific young offender (mid-point: £55,000 per year) • £215,000 per year for place in secure children's home	Criminal Justice System, the Exchequer and wider society	Flint *et al.*, 2011

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
Encourage siblings to attend school and undertake ‘normal’ activities	Sibling(s) may be reluctant to attend school (possibly due to bullying) and start truanting	Significant truanting from school can have life-long adverse effects due to lack of qualifications Ofsted have calculated the additional annual costs of educating a child with emotional, behavioural and social difficulties (EBSD). It should also be noted that many problems associated with poor educational attainment and inappropriate/ criminal behaviour may also be linked to family breakdown/failure.	• £2,819 for involvement of Education Welfare Officer (higher if court costs) • Over £7,000 per year net cost of alternative provision for excluded pupil • £44,500 total cost (social and individual) of persistent truant • £64,000 total cost (social and individual) of school exclusion • £56,000 (present value) average life-time public finance cost of being NEET (Not in Employment, Education or Training) in late teens • £104,000 (present value) average life-time resource cost of being NEET • Cost of educating child with EBSD: £1,078 in primary school and £3,234 in secondary school	Education, the Exchequer and the individual	LGL/WCC, 2010; Flint *et al.*, 2011 Ofsted figures from Copps and Heady, 2006

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
FAMILY SUPPORT					
Provide support to parents (and wider family) to help them continue their caring role	Reduce risk of parents developing short-term or chronic problems with physical health	Costs vary considerably with the nature and severity of health problem. Costs given are therefore indicative only.	• £32-£47 for cost of GP consultation/visit; £41 prescription costs per consultation • £116 per outpatient visit • £443 per inpatient bed day • £535 per non-elective short inpatient stay • £2,267 per non-elective long inpatient stay • £110 per visit to A&E • £257 per emergency ambulance journey • £250-£300 per day (alternative estimate of day cost figure from NHSI/DH)	Cost to NHS / Exchequer	PSSRU, 2007; PSSRU, 2008; LGL/WCC, 2010; NHS Reference Costs 2008/09; Department of Health quoted in NHSI, 2010

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
	Reduce stress and anxiety and need for help with mental health problems		• £32-£47 for cost of GP consultation/visit; £41 prescription costs per consultation • £2,740 cost of IAPT(Improving Access to Psychological Therapies) counselling course • £253 national average unit cost for first appointment with mental health consultant (£156 for follow-up appointments)	Cost to NHS / Exchequer	LGL/WCC, 2010; NHS Reference Costs 2008/09
	Ensure family is aware of all the benefits to which it is entitled (e.g. Disability Living Allowance; Carers' Allowance) and is claiming them	Family may need help from FSW to understand and complete forms (other staff - such as nurses and Social Workers – may not have time)	Depends on what is already being claimed. Disability Living Allowance: care component £19.55-£73.60 per week; mobility component £19.55-£51.40 per week.	Cost to Exchequer Benefit to family	Current rates taken from www.direct.gov.uk

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
	Reduce risk of family breakdown and all of the possible associated financial and other consequences	Housing costs – including costs of renting, equipping and running two households. One or both households may also be entitled to Housing Benefit and/or Council tax Benefit (much more likely to apply to lone parents than couples)	• Rent: £50-£100 per week (estimate) per property • Equipment and Running Costs: £200-£400 per month (estimate) per property • £89 per week – average Housing Benefit payment • £15 per week – average weekly Council Tax Benefit • £1,364: annual cost of family breakdown for every taxpayer	Family Local Authority/ Exchequer may need to cover costs of temporary housing if re-housing necessary	Relationships Foundation, 2011
		Social care costs – child protection	£5,000 for Child Protection Plan	Local Authority/ Exchequer	LGL/WCC, 2010
		Social care costs – foster care	Average of ~£900 per week £33,000-£70,000 per year	Local Authority/ Exchequer	See LGL/WCC Flint *et al.*
		Costs associated with Domestic Violence	£23,200 per year		Department for Education Negative Outcomes Tool, reported in LGL/WCC
		Legal and other costs of sorting out child maintenance contributions, visiting rights etc, and possibly of divorce	Not estimated	Family and/or Exchequer	

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
		Additional benefit payments to lone parents	Not estimated	Exchequer	
		Also see above for potential long-term effects of family breakdown on educational attainment and on civil and criminal justice			
Provide support to enable one parent to continue working (or take less unpaid time off work – e.g. for hospital appointments)	Helps maintain household income, or limit its reduction, and may prevent job loss. Self-employed parents will not have access to sick pay or compassionate leave (although hours of work may be more flexible)	Family finances are under extreme pressure when caring for a sick child. Actual financial impacts will be family-specific, but the following figures indicate the potential opportunity costs of not working. Earnings vary by age group and there are also regional differences.	• £6.08 per hour: minimum wage rate for workers aged 21 and over (from 1/10/11) • £12.50 per hour: average gross hourly earnings (Full-time: £13.01 for men and £11.68 for women; part-time: £769 for men and £8.00 for women) • £499 per week: average gross earnings for full-time employees (£538 for men; £439 for women) • £154 per week: average part-time weekly earnings (£157 for women; £142 for men) • £25,900 per annum: average gross annual earnings for full-time employees (£28,100 for men; £22,500 for women)		Minimum wage rates from www.direct.gov.uk Office for National Statistics, ASHE 2010 (figures are median values for April 2010 or the 2009/10 tax year – should be uplifted by about 2% for 2011 values)

Intervention	Main Benefits	Other Relevant Points	Financial Consequences	Financial Beneficiaries	Source of Cost Data
	Debts can be a problem for households with a disabled child		• Debts of £500-£1,000 for 52% families and £1,500-£5,000 for 23%		Harrison and Wooley, 2004
Additional costs to families of a disabled child	Additional expenditure required for transport costs, clothing, bedding and laundry, replacement furniture, mobility equipment/housing adaptations, and food		• £105 per week and £5,440 per annum		Wooley, 2004
END-OF-LIFE SUPPORT					
Provide support to enable the sick child (where feasible) to die at home rather than in a hospital or hospice	Ability to contribute intensively during the end stages of life, providing support to all members of the family and enabling the child to die in familiar surroundings (with nursing care provided by appropriately trained community-based professionals)	May be less expensive for a child to die at home rather than in a hospital or hospice. Parents would often prefer their child to die at home, but they need to feel confident that they can cope – the support of their familiar FSW can provide the necessary reassurance	No estimated costs are presented as these will depend on the circumstances of each child and the available local alternatives		
BEREAVEMENT SUPPORT					
Provide support to all family members after the death of the sick child	May help to reduce stress and strain felt on bereavement, which in turn may help to keep the family together (and prevent family breakdown and all of its consequences). May also reduce the need for medical help and pharmaceutical interventions.				

Section 5: Discussion and Conclusions

5.1 DISCUSSION

The previous sections have considered various aspects of the work of Rainbow Trust's Family Support Teams (FSTs). The FSTs provide emotional and practical support for families who have a child with a life-threatening or terminal illness. The study focuses on exploring some of the economic and financial consequences of its work. Although it is impossible to know what would have happened to a particular family in the absence of support from Rainbow Trust, a review of relevant published papers and reports and the experiences of the Managers of the FSTs identify many adverse events that may have occurred without the intervention.

The literature stresses the importance of providing carers with short breaks from their roles to enable them to withstand the pressures and stresses that they face. Such support is valued by families and may help the family to care for the sick child at home. The literature also shows that home-based care can often be viable and is usually less expensive than institutional-type care (although it recognises that some time in hospital may be inevitable). Additionally, it is also generally preferred by families.

The analysis of the activity and cost data provided by Rainbow Trust shows some marked variations in these across the FSTs. For example, the average total cost per family (which includes care costs and core costs) is almost £2,500, but ranges across the FSTs from about £1,500 to just over £4,000. There may be many valid reasons for these differences (such as Team size, area covered, and Team maturity), but we suggest that Rainbow Trust explores these to see if there are any aspects where some FSTs could learn from the characteristics and practices of the others. The data analysis also provides breakdowns of the costs to show the average costs of the different types of support provided by the FSTs. Although these costs will depend on the ways that the Family Support Workers (FSWs) classify their hours of work (given that several types of support can be provided simultaneously), the analysis may also identify some interesting differences across the FSTs. For example, some FSTs only seem to provide limited bereavement support. This may reflect a need for some additional training in this area of support, or it may be due to the characteristics of the families being supported during the year by the FST, such as relatively few with children dying of terminal conditions during the year.

The discussions with the FST Managers reinforced the findings of the literature review and showed some of the main benefits of their support. These can range from very practical activities, such as taking family members to hospital visits and clinic appointments, to providing emotional support that may help prevent the stress of caring causing mental and physical health problems. Such support may also help prevent family breakdown, which can have far-reaching effects on families. Families with a sick child will face many financial pressures, especially if one or both parents have to reduce their hours of work or cease working completely.

It is interesting to compare the average cost of support per family with some of the costs that may have been prevented by the support (see Section 4). It should also be remembered that the average cost of £2,500 per family will be spread over several family members – so the cost per person for a family of two parents and three children will only be £500. Although we cannot identify the precise benefits of the support provided by the FSW, we can be certain that all families (and all family members) will benefit in a variety of ways from their involvement. Help with transport to and from hospital can save a family several hundred pounds over a period of time. Preventing the need for a GP visit because of concerns about physical and/or mental health can save about £85 per visit for the NHS (this covers the cost of the consultation and prescribed medication). With an average cost per hospital bed day estimated as £250 to £300 (or possibly as high as about £450), a three-day stay in hospital can cost the NHS from about £750 to £1,500. A series of counselling-type sessions for mental health problems such as stress and anxiety can cost the NHS about £2,750. Visits to specialist mental health professionals can cost the NHS at least £250 per visit, and often considerably more. For example, the national average cost of a first outpatient mental health consultant appointment is about £436 (and £257 for follow-up appointments). Set in this context, an average cost of about £500 to £1,000 per family member seems to provide very good value for money.

There are, however, many other costs that may also be prevented by the work of the FSTs. Foster care for a child can cost an average of about £900 per week (or over £45,000 per year). Early recognition and management of problems associated with poor school attendance or performance (e.g. by siblings) can result in considerable cost savings – for example, involvement of an Education Welfare Officer can cost over £2,800. The long-term cost consequences for the child and the state of truancy and poor educational attainment can be over £50,000. Behavioural problems in young children can develop into challenging behaviour and anti-social behaviour, which may include criminal activity. The average cost of a crime by a young person is £4,600; annual costs for prolific offenders can exceed £50,000. Family breakdown increases the likelihood of educational and behavioural problems.

Although the FSWs do not provide financial advice directly, they often help families claim the money to which they are entitled (by, for example, helping them complete forms and attend meetings). Disability Living Allowance can increase a family's income by over £100 per week. A Family Fund grant may enable the purchase of a much-needed item, such as a washing machine (which could cost at least £200 to purchase). With average gross full-time earnings being about £500 per week, and about £28,000 per year for males, providing support that enables a parent to continue in paid employment has a significant impact on household income.

These are examples of just some of the areas where considerable cost savings may result (at least in part) from the involvement of an FST. Staff at Rainbow Trust could use the costs presented in Section 4 to construct profiles for some of their families. These would help to provide a realistic picture of the extent of the savings that may be achieved, based on the experiences of real families.

5.2 CONCLUSIONS

Rainbow Trust provides a unique support service through its FSTs. These Teams have many valued features, including:

- Providing holistic care and an holistic approach;
- Working with all family members (including siblings);
- Providing tailor-made emotional and practical support, led by the wishes of the family;
- Being flexible and responsive – the support changes as family needs change;
- Providing support that is not time-specific or time-limited;
- Provide continuity over a period of time when a family may come into contact with many different people from other agencies).

As well as providing support with current issues and problems, the FSTs can also prevent problems from developing through seeing the family on an ongoing basis in many settings, including the home. They can then take appropriate action, such as contacting other relevant agencies for help. Where the FSWs are unable to provide a particular type of help themselves (such as financial advice), they can signpost the family to the appropriate agencies. Their work is greatly valued by the families (and also by other agencies).

At an average cost of about £2,500 per family (or £500 per person for a family of five), the work of the FSTs provides excellent value for money when compared with the types of costs that may otherwise have been incurred by the family or other stakeholders (such a statutory service providers) in the absence of Rainbow Trust's involvement. Such costs could easily exceed £10,000 in the short term, and be much more than this if there are long-term consequences for family cohesion, health, educational attainment and behaviour.

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- Local Government Leadership/Westminster City Council;
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Appendix A

A.1 INTRODUCTION

This section draws on both peer-reviewed publications and grey literature, as well as evidence collected by YHEC for their Economic Study (Lowson *et al.*, 2007) supporting the Department of Health's Independent Review of services for children with palliative care needs (henceforth referred to as the IR Economic Study). We are interested here in what the literature tells us about models of care for managing children with complex needs and life-limiting conditions.

Before we address the literature we need to make two observations. Firstly, the literature on this group of children can be limited and many of the issues affecting them and their families are similar to those faced by children termed as disabled: in other words, this group of children is a subset of a larger group. Therefore, much of the relevant literature discusses issues faced by disabled children and their families.

Secondly, the literature addresses a wide range of models of care including hospital, hospice and residential care. We have focused on what is often termed as respite care, or short breaks, but it has often proved difficult to disentangle 'home care' (as delivered by the Rainbow Trust) from other methods of delivery, such as short-term residential care or care in day centres. We also acknowledge that Rainbow Trust do not consider that they deliver 'respite', and that this term is not normally used by those who deliver or commission such services. However, the literature that we have examined covers US and UK services and many relevant articles were published during the late 1990s and thus much of the literature refers to respite care which includes the home-based model of care delivered by the Rainbow Trust.

This section explores what the literature tells us about the financial, physical and emotional burdens faced by families of children with disabilities, as well as the costs, benefits and challenges of different models of care.

A.2 BURDEN OF CARE

The additional burden of care on families with disabled children is well documented. This extra burden can be financial, through additional costs or loss of income, and psychological. Extra costs to families with severely disabled children were estimated (at 2004 price levels) to be around £105 per week or £5,440 per annum (Woolley, 2004). Additional expenses included transport costs; clothing; bedding and laundry; replacement furniture; mobility equipment or housing adaptations; and food (Woolley 2004, Harrison and Woolley, 2004). Families with a disabled child have been estimated to spend around one-fifth of their income on goods and services for their disabled child, excluding food (Dobson, 2001). On average they spent around £66 on everyday items (including activities, clothes, toiletries, medical items and children's possessions, but excluding food) for a disabled child (at 2000 price levels), compared with an estimated £31 for their other children. Thus there appears to be a shortfall in spending on those children who are not disabled on items such as clothes, activities and other possessions. These expenses on disabled children were similar to those described by families in focus groups run by YHEC for the IR Economic Study. Examples of the additional expenditure, over and above what focus group members considered to be the expected additional costs of bringing up their child, are shown in Box A.1.

Box A.1: Expenditure reported by parents attending the focus groups for the IR economic study

- In one group of parents, all had bought at least one baby monitor and one parent had bought three;
- One family had re-mortgaged their house to raise £30,000 for adaptations and two families had received between £75,000-£90,000 for adaptations;
- One family bought an adapted car for £13,000, and another family bought specially adapted car seats for £600;
- One family bought a special wheelchair for £1,500;
- One family took their child and the siblings on five occasions for Dolphin therapy in Florida at a cost of £6,000 per visit.

Source: Independent Review Focus Groups.

Transport costs are reported to be a particular burden in several studies. Macmillan Cancer Support in their study (MacMillan Cancer Support, 2006) of the transport costs incurred by patients (adults and children) with cancer reported that 70% of cancer patients face extra costs in order to receive their treatment; 58% face travel costs to get to their treatment centre and 45% face parking costs whilst having treatment. Amongst patients incurring travel costs, the average number of trips made in the course of their treatment was 53, and the average cost for travel and parking was £325 per patient. Over three-quarters (78%) of those incurring travel and/or parking costs received no financial help with these costs.

Families in the YHEC focus groups also reported having particularly long journeys - often of several hundred miles - as they frequently had to take their children to specialist centres which could be in London. Many highlighted the high costs that they could incur when using vehicles obtained under Motability schemes with a ceiling on miles funded. These ceilings could easily be exceeded if a child required treatment at a distant hospital. They also reported on the costs of parking, including receiving penalty notices and fines for parking incorrectly, usually due to a shortage of parking at hospitals. Despite appealing to councils, most had to pay these fines.

Corden *et al.* (Corden *et al.*, 2001 and Corden *et al.*, 2002) reported that reducing hours at work or giving up paid work to manage a child with disabilities could result in significant reductions in the family income. Lone parents found particular difficulties in maintaining paid employment. None of the families in their study were able to undertake paid work during the final years of a child's life. All families faced additional spend, including higher fuel and telephone bills, and running a suitable and dependable vehicle. These studies also highlighted the serious financial problems faced by families in the period immediately after the death of a child as a result of the loss of benefits. This could contribute to a loss in monthly net income of around 14% to 25%, whilst for a lone parent relying on income support; the income loss could be as high as 72%. Patterns of expenditure formed during a child's life were difficult to change and many families in their study became in debt. The authors also commented on the emotional problems associated with the changes in financial status:

> "…*for some, the withdrawal of benefits seemed like society's acknowledgement that their child's life was over. The way in which this was dealt with was important and insensitive treatment increased pain and grief".*

These studies highlighted the need for financial advice and support to families both during and after their child's lifetime.

In an estimation of the levels of debt in families with disabled children (Harrison and Woolley, 2004), families with disabled children were four times more likely to have debts and 61% of families surveyed stated that they believed that this was due to having a child with disabilities. Over half (52%) of the families surveyed were estimated to owe between £500 and £10,000 and 23% between £1,500 and £5,000 (at 2004 price levels).

Beresford (Beresford, 1993) investigated the impact of a Family Fund grant on mothers caring for a severely disabled child. Using measures of care-related stress and maternal adjustment, she found that the receipt of the grant had a significant impact on perceptions of stress in caring for the child as well as improving the mother's well-being and maternal adjustment. However, she also found that receipt of the grant did not appear to improve perceptions of the child's disability or the extent to which the disability had adversely affected the personal lives of the family.

A.3 COMMUNITY SUPPORT AND SHORT BREAKS

A.3.1 Models of Care

Traditionally, respite services have been associated with the idea of relieving carer burden (Cotterill *et al.*, 1997). Increasingly, in the UK, the concept of a 'short break' is being adopted, rather than the term 'respite care'. However, the models of home support offered by the Rainbow Trust are frequently subsumed within the terms respite or short breaks in published evaluations and reports. We, therefore, have to refer frequently to respite care in this summary of relevant literature. (See our note at Section 1.3 above).

A transformation programme for disabled children's services in England, Aiming High for Disabled Children (AHDC), was launched in 2007 with the objective of improving services for disabled children and their families. It was backed by substantial funding from the then Department for Children, Schools and Families (now Department for Education). AHDC identified short breaks as the highest priority service for families with disabled children, and the majority of the AHDC funding was allocated to short breaks (an evaluation of the pathfinders having been undertaken). It is noted that the recent evaluation of the Short Breaks Pathfinder sites (Greig *et al.*, 2010) highlights "*the imprecise nature of short breaks"*, in part due to the lack of clarity of what constitutes short breaks.

Respite care or short breaks have several functions: they can give a child an opportunity for additional experiences outside the family home; they can support carers of the child; they can prevent family breakdown and/or rejection of the child; and they can avoid the possible admission of the child to long-term care or the necessity to find a substitute family placement (Hoare *et al.*, 1998). As stated by Hosburgh *et al.* (Hosburgh *et al.*, 2002):

> "*It is essential to find relief from the intense role as a carer in order to continue the role. Without this, marriages fail, siblings suffer and families disintegrate*".

Such care can be offered in a variety of settings, including hospital or hospice. However, increasingly it is being delivered in the community, including in the child and his/her family's home.

Hoare *et al.* (Hoare *et al.*, 1998), in their survey of children with severe intellectual disabilities and their families, undertook a basic literature study. They found that despite the potential benefit of respite care, an important constraint is the availability of resources, which in turn is dependent on the priority allocated to the service by the health and social services. Robinson and Stalker (Robinson and Stalker, 1993) found that access to services was uneven, and the type and amount of respite also varied with the disability of the child. Even when respite care was available, services were often criticised for the quality of care provided and the lack of understanding of the emotional needs of the parents and siblings. Evidence indicates that there are beneficial effects, particularly for mothers; however, some studies suggest that the children may not always benefit, or may receive less stimulation.

Treneman *et al.* (Treneman *et al.,* 1997) showed that respite care could be perceived as an inadequate service. Their recommendations were in respect of improved information provision (88% of respondents in their survey had no knowledge of respite services), choice, flexibility for carers and for improved quality standards. Campbell (Campbell, 1996), via a survey of families in Scotland, identified a need for additional respite services, as many of the children of families surveyed appeared to have inappropriately received care in hospital settings due to the lack of alternatives.

Cotterill *et al.* (Cotterill *et al.*, 1997) undertook a literature review focusing on the models and methods of delivery of respite care. They found that increasingly the aims of respite services were coming under closer scrutiny and were being framed around the needs and wishes of service users, recognising that the experience should be positive for the user and carer. They also report that the experience of the user is a crucial ingredient in the evaluation of the quality of the service, and the nature of the benefits it brings to service users and carers. Robertson *et al.* (Robertson *et al.,* 2010) also undertook an international literature review of the impact of short break provision on families with a disabled child. They too found that the research consistently reported a positive impact on the well-being of most (but not all) disabled children and their families.

Studies have increasingly focused on the home as the preferred location of provision for children with complex needs (Olsen and Maslin-Prothero, 2001). Providing respite care in hospital is seen as cost ineffective compared with respite in a child's own home, together with the positive influence of the home environment on children's recovery and well-being. Olsen and Maslin-Prothero undertook an in-depth study of the provision of own-home respite support for families with children with complex needs. This was developed, in part, as a response to parents' concerns about residential care. The results demonstrated that parents valued respite care, but only as part of a package, with other factors and services having an equal impact on family well-being. The evaluation also demonstrated that the services offered had to be extremely flexible to meet the differing needs of the families. The problem for the providers of the evaluated services was the balance between the unpredictability of children's and families' needs against the requirement to have planned provision of services. However, as Olsen and Maslin-Prothero stated (p609).

> "…*more worryingly, we found that some parents talked about losing faith in the service entirely on the ground of the lack of flexibility it offered*".

Damiani *et al.* (Damiani *et al.,* 2004), in a study of respite care for families of, and children with, cerebral palsy, reported that 46% of the 468 caregivers interviewed used respite care, and most caregivers who used respite care also used services provided in the home. Over 90% of caregivers indicated that respite use was beneficial for both their family and child; but over 60% reported experiencing barriers while attempting to access respite services. Corkin *et al.* (Corkin *et al.,* 2006) also emphasised the value of respite care, asserting that without an occasional break parents are likely to become completely exhausted or unwell due to the constant physical, psychological and social demands of caring.

Therefore, in summary, community and home-based respite care is seen by providers, families and evaluators as the direction of travel, despite the problems in offering services that are valued by the families.

A.3.2 Costs of Community-Based Care

Short Break Home Respite is a model described in detail in Copps and Heady (Copps and Heady, 2006). This model comprises breaks for families through the provision of carers in the families' own homes, who are supported by social workers from their Local Authority Social Services (LASS). Information collected by Copps and Heady indicates that the overhead costs of supporting a carer are around £5,400 (per carer), assuming that one social worker supports a caseload of 20 short break carers. They have calculated the pay per 24 hour period for a carer is £44 and the total cost per family per annum, assuming that children receive one day's break per week plus one week per year (a total of 57 days per annum) is £6,630, assuming that, on average, a carer cares for 1.3 children. They also indicate that the range of costs reported by other studies that they reviewed varies from £37 to £284 per night, with one survey of councils in the South West of England calculating the cost to be £60 per night. The cost per night calculated by Copps and Heady is £116, indicating that the overhead cost for supporting the carer is greater than the wage paid to the carer.

YHEC analysed data for their IR Economic Study on community support teams funded by the Big Lottery. These community support care teams were newly set-up services offering home support. The analysis showed that the average size of a team was between 2.5 and 5.5 whole time equivalent (wte), and they were funded for three years at a cost of around £133,000 (at 2006 price levels) per year. The teams comprised different combinations of staff, usually community nurses and/or health and social care staff, together with social workers, psychologists, OTs and physiotherapists. The former groups tended to be full time or nearly full time, whilst the latter tended to be 0.1 to 0.2 wte. Some teams also had administrative staff. The number of children and families supported by a team ranged from 15 to 52, with the majority around 24 to 30. Thus the average number of families per wte team member ranged from 3.7 to 13, with the majority between 5 and 7. The cost per family supported ranged between £2,600 for a team that supported over 150 families to around £8,900 for a team that supported 15 families. The teams also undertook other activities such as training sessions, and supporting other professionals, but these activities were not necessarily quantified and hence not costed.

A.3.3 Cost Effectiveness of Home-Based Support Care/Short Breaks

A major problem with analysing the evidence on the cost effectiveness of home-based support care/short breaks is extracting the evidence on home-based models of care: much of the evidence across the models, (for example, home, day centre and residential) is combined or summarised together. A second problem is identifying models that use staff other than trained nurses. A third problem is the paucity of cost-effectiveness studies on these models of care.

Nef Consulting (Nef Consulting, 2009) estimated the social and economic value of short breaks (but without differentiating between the different models of delivery of support). Their report (p1) states that:

> *"…short breaks provide families with a mechanism by which to cope with the pressures of caring for a disabled child. This has an indirect impact on the family environment in terms of less stress for the parents and more time for other siblings, which can be translated into a higher sense of well-being for the family as a whole".*

They further assert (and calculate) that there are: financial savings from the reduced likelihood of a disabled child being placed in care; a reduction in health costs and increased taxes (since families are more likely to keep working) due to the reduced stress of parents, families and carers; and a cost saving due to the likelihood of a possible reduction in problems with siblings' schooling as a result of the parents being able to spend more time with the siblings. They calculate the potential financial savings from short breaks (although acknowledging that they have not taken account of other activities arising from Aiming High for Disabled Children which could contribute to these savings) if they were made available to all disabled children in England for whom they are appropriate (see Box A.2).

We acknowledge that the first category of savings in unlikely to be addressed by the services offered by Rainbow Trust; however the second and third categories will be. The calculations on estimation of prevented GP visits assume that the average cost of a GP surgery consultation with prescription is £76 per visit, that the proportion of extra stress attributable to caring for a disabled child is 75%, and that only 21% of disabled children receive short breaks. The calculations of savings associated with reduced sick days assume that the average cost of lost corporation tax per sick day is £15.82, applied to two extra sick days per year, with the same percentages for stress and receipt of short breaks. Having a disabled sibling is estimated to double the chance of a child displaying emotional, behavioural and social difficulties (EBSD) (Copps and Heady, 2006) and 4.3% display EBSD. Ofsted estimates that the extra cost per annum of educating children with EBSD in primary schools is £1,078 and that for secondary schools is £3,234 (Copps and Heady, 2006).

It should be noted that these calculations apply to all disabled children, rather than specifically to children with life-limiting conditions and complex needs. However, Rainbow Trust may find the methodology for calculating these savings useful in persuading commissioners to fund their services.

Box A.2: Estimated financial savings for the state from full coverage of short breaks provision

Outcome	**Value**
Decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family home	£135,008,061
Decreased cost to health service from reduction in parents', families' and carers' stress:	£17,610,108
• Cost savings stemming from reduction in GP visits	£11,647,947
• Cost savings stemming from reduction in sickness absence	£5,962,161
Decreased cost to schools of educating siblings with behavioural and emotional difficulties	£21,370,271
Total	**£173,988,440**

Source: Nef Consulting (2009).

A.4 BEREAVEMENT SERVICES

Bereavement services are provided for parents who have lost a child, or for children who have lost a sibling. Rolls and Payne (Rolls and Payne, 2003) in their review of bereavement services for children indicated that 85% are provided by the voluntary sector, with 14% being dedicated bereavement services for children. Most are small scale - for example, just over 50% of the services managed less than 49 cases per annum. Slightly less than half (44%) of the host organisations were hospices, and whilst the majority of services (73%) used both paid and unpaid staff, 14% relied entirely on unpaid staff. The interventions provided were wide ranging, including individual and group work with families and children, as well as pre-bereavement support, information and advice, and training. Three-quarters (74%) also offered services to other organisations such as schools and other professionals.

Evidence suggests that pre-bereavement planning is essential. For example, Matthews *et al.* (Matthews *et al.,* 2006) report on the development of the Liverpool Care Pathway for the dying child. Because the death of a child in most industrialised countries is relatively rare, the limited experience of health professionals in caring for the dying child and their families may be problematic. Sahler *et al.* (Sahler *et al.,* 2000) discovered that health professionals may react by being emotionally and physical distant from the dying child and their family at a time when support is needed most. They suggest that all health care students should be trained to manage this situation.

Kopecky (Kopecky,1997) reports, in a review of literature on place of death, that the majority of studies declare that the most appropriate place of death for a child is the family home, provided that this is the choice of the family and that adequate support systems have been established in the community. Research by Kristjansen *et al.* (Kristjansen *et al.,* 1996) suggests that the families' care experience during the palliative care phase has a bearing on family members' health and the families' ability to function during the early bereavement period.

Lenton *et al.* (Lenton *et al.*, 2004) report on the development of the Lifetime Framework for engaging with families to decide end-of-life plans for children. They developed a three-by-three matrix covering before, at, and after death, and focusing on the child, their family as well as extra-familial others, such as their school and their friends. This approach also has a wider focus than just physical symptoms and develops an holistic approach including preference for place of care and death, and preferred outcomes.

Hannan and Gibson (Hannan and Gibson, 2005), for example, examined how parents decide on the place of care and death for children dying with cancer. Firstly, families valued time left with children in deciding their place of care and death and, therefore, normally wanted their child to remain at home, in part to retain normality, but also because that was what their child often wanted. Secondly, families wanted to feel safe and secure, having control but also wanting support. This led some families to choose hospital in the absence, or knowledge, of good community support. Thirdly, families did not know what to expect (hence the need for good end of life planning). For example, knowing how long a child will live is important. Although difficult to predict, Hannan and Gibson report on literature which indicates that having a child living longer than expected is emotionally and physically problematic, and conversely if the child dies sooner than expected the family feel cheated of time spent with their child. Fourthly, there is a difference in the way that services are offered between specialist and non-specialist staff. Hannan and Gibson report on poor experiences of families, for example at weekends, when their specialist Paediatric Oncology Outreach Nurses (POONs) were not available.

Hunt (Hunt, 1998) suggests that non-specialists should be trained and empowered by specialists. Hannon and Gibson recommend that there should be outreach nurses, and that staff should be trained in the management of paediatric palliative care. This is crucial where teams of community paediatric nurses manage palliative and acute cases. They further speculate as to the amount and quality of death education that is received in children's nurse training. However, despite evidence about the need to manage the end of a child's life, there is less certainty about the provision of bereavement services, where literature indicates that only some families benefit from such services. Rowa-Dewer (Rowa-Dewer, 2002), for example, examined whether the provision of bereavement support for parents who have lost a child leads to better subsequent adjustment. She reported that no overall benefit for the interventions was shown, although psychological symptoms and marital dysfunction were significantly reduced for highly distressed mothers. There were also disparities in the findings, such as the effects of interventions on fathers, which may be explained by flawed methodology. However, applied to practice, these findings suggest that only some bereaved parents benefit from bereavement support programmes, and therefore a targeted approach may be the best use of resources.

The analysis by YHEC of bereavement services funded by the Big Lottery Fund[13] (unpublished data) indicated that there are several adopted models. One model comprises many (one scheme had 19) individuals working part time, a second model comprised a small number working part time (between one and three) and a third model had social worker support for volunteers. The number of families supported ranged from 9 to 92, with an average cost per family ranging from £270 to £2,700.

A.5 COMPARATIVE COSTS OF CHILDREN'S DEATH

In the IR Economic Study YHEC examined the burden falling on inpatient expenditure as a result of the management of conditions likely to lead to the need for palliative care. Using 2004/5 Hospital Episode Statistics (HES) data and Healthcare Resource Group (HRG) categories and costs (which means that they are not directly comparable to bottom-up costs calculated using the most up-to-date Reference Costs), the analysis shows that around 16% of the spend and 16% of the Finished Consultant Episodes (FCEs) are in respect of neoplasms and their management, such as bone marrow grafts and chemotherapy. However, the majority of children diagnosed with malignant and non-malignant neoplasms do not require palliative care treatment. The costs of other conditions which are likely to lead to an eventual need for palliative care are shown in Box A.3.

Box A.3: Costs and activity associated with conditions likely to require palliative care for children

Healthcare resource group	**Expenditure £'000 (2004/05 prices)**	**FCEs**	**Cost per FCE**
Congenital, major & other congenital disorders (E43+P19+P20)	42,461 (8.0%)	16,029 (6.3%)	£2,648
Cardiothoracic procedures (E41)	16,857 (3.1%)	3,009 (1.2%)	£5,602
Cystic fibrosis (P02)	10,562 (2.0%)	5,404 (2.1%)	£1,954
Nervous system disorders (P09 + A34)	13,406 (3.0%)	6,269 (3.0%)	£2,138
Developmental disorders (P18)	7,547 (1.4%)	2,001 (0.8%)	£3,772
Total	**90,833 (18.0%)**	**32,712 (13.0%)**	**£2,777**

Source Cochrane *et al.*, 2007.

Evidence from alternative models of care indicates that more children could be managed away from hospital inpatient facilities and/or their lengths of stay could be reduced which could lead to the release of valuable resources. The above figures represent around £460,000 spend and 166 FCEs per locality of 250,000 population. Assuming there are between 50-80 children with life-limiting conditions (LLCs) in this population (using data from Lowson *et al.*, 2007), this represents between 2.0 and 3.3 FCEs per annum per child with a LLC.

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[13] The University of Warwick generously gave YHEC access to their unpublished data.

Analysis of location of death for children and young people with conditions likely to have required palliative care demonstrates that not only do the majority of those aged 0-19 years (excluding neonates) die in hospital, but there are also great variations in where these young people die. Yet, most families prefer their children to die at home. Analysis of deaths for the IR Economic Study (using 2004/05 data) indicated that if the percentage could be increased to that of the (then) best performing Strategic Health Authority (in which at least 25% of children died at home), then this would reduce the number dying in hospital by around 410 per annum. At an average cost per episode of care of £2,000 (using those healthcare resource groups for 0-19 year olds with a primary diagnosis indicating a condition likely to lead to an eventual need for palliative care, at 2004/05 price base), this would generate around £864,000 of resources which could be targeted towards community services. A further 5% reduction of children dying in hospital would equate to a further 370 children being able to die at home, generating around a further £782,000 to £1.03m for community services. The analysis also indicated that children with life-limiting conditions are living longer and therefore the number of hospital visits by these children and young people, and hence resources utilised, is likely to increase as the prevalence rates increase.

Alternative methods of managing these children away from hospitals normally require input from community nursing services. However, community support services, such as those provided by the Rainbow Trust could support these families in managing their children at home. For example, technology-dependent children can be managed at home rather than as an inpatient.

A.6 RECOMMENDATIONS FROM THE INDEPENDENT REVIEW ECONOMIC STUDY

In YHEC's IR Economic Study, taking the evidence overall for what was termed in that report as community respite, it was strongly recommended that a package of comprehensive services for children with life limiting conditions and complex needs should include, as a priority, community respite services. Indeed, these services were rated as the second most important after the provision of a paediatric palliative care nursing team.

YHEC has identified three (or indeed more) models of delivery of community respite care. One model is that provided by the voluntary sector; the second is that provided by lower grade nurses or health care support workers through community nursing teams; and the third is provided by a commercial organisation. There are also three models of funding: through donations and fundraising by the voluntary sector; through statutory funding; and through the direct payment mechanism in which families receive payments and purchase the services that meet their needs. Under the latter mechanism, families may also purchase services provided from both commercial and voluntary sector organisations.

Using the evidence that was collected from service providers in YHEC's IR Economic Study, it was estimated that a support worker could support 15 families and therefore a team of five support workers would support 75 families, in a 250,000 population. This level of resource would deliver an average of 2.5 visits per month, but would not be able to deliver the sustained 6 hours per week of home care to each family every week (as recommended by ACT), the majority of which are likely to be covered by the direct payments scheme.

It was estimated that such a team would cost around £113,000 for a population of 250,000. This would equate to £22 per hour (as calculated by Joy, 2006 and uplifted). Therefore, a team serving a population of 1 million would cost around £452,000 per annum. The service itself could be delivered by one or several organisations in the voluntary sector. There are many such organisations already established, often with a niche focus, and it is likely that the voluntary sector has the expertise to deliver such a service. A more effective approach, therefore, in ensuring that a comprehensive service is available within a locality is, rather than establish a new service, ensure that those organisations in the voluntary sector already providing such services are linked in to the strategic planning of palliative services. It is also important to ensure that the whole population has equal access and hence strategic planning would identify gaps.

Such a team or teams could be funded in part by a PCT, in part by direct payments and in part by the voluntary sector. For example, the PCT may choose to fund bereavement services. The estimated number of bereaved families, assuming that 10% of children die each year will be between 20-30 in a population of 250,000. Additionally, bereavement services that we investigated for the IR Economic Study would probably support a family for up to two years after the death of a child, so a population of 1 million would probably comprise 60-90 families who would benefit from such services. The estimated cost of providing a bereavement service as funded by the Big Lottery Fund (unpublished data) was £25,000 per annum, and the number of families supported by these bereavement services varied, but two services supported between 77 and 92 families. Therefore, we estimated that bereavement services for this population of 250,000 would cost around £25,000 per annum.

The evidence indicates that supporting carers and their families who manage children with complex needs and life limiting conditions at home can be cost effective. The evidence also indicates that families prefer their children to be managed and to be able to die at home. Costs that can be avoided or reduced include inpatient and residential care for children and stress-related healthcare, such as GP visits or medication for family members, as well as societal costs such as marital breakdown or loss of productivity as family members are unable to work.

Evidence (see, for example Cotterill *et al.,* 2007, and Robinson *et al.*, 2010) also indicates that the model of home care support offered by Rainbow Trust is also valued by families who prefer flexible care delivered in their own homes to a more rigid model of short term residential care.