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What price an ordinary life?

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**The financial costs and benefits of
supporting disabled children and their families**



The True Colours Trust

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This report has been funded by The True Colours Trust.

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Summary

This report quantifies the **financial costs and benefits** of supporting disabled children and their families. It focuses on two services: short breaks and key workers.

Costs

The unit cost of short break and key worker services are calculated using evidence from two national surveys. For short breaks, costs are calculated for shared care schemes using volunteer carers. Costs are given per average disabled child.

Benefits

The first step in calculating financial benefits is to identify costs which might be prevented if families had access to services. These costs are:

- the cost to the family from parents not being in work;
- the cost to employers from parents' stress (sick days);
- the cost to the health service from parents' stress;
- the cost to schools from educating siblings with emotional and behavioural difficulties;
- the cost to social and educational services of caring for a disabled child outside the family home (foster care or residential placement); and
- the cost to the family of separation and marital breakdown.

The second step is to determine the benefits by using a proportion of these preventable costs. These proportions are based on a number of assumptions, all of which are laid out clearly in the text. Benefits are given per average disabled child.

Short break services

For the average child, **short break services** cost £6,635 per year, or £81,584 over fifteen years. Nearly two thirds of this cost comes from management and overheads.

A sober estimate of the financial benefits to society of short break services is £2,505 per year, or £30,737 over 15 years.

Key worker services

For the average child, **key worker services** cost £2,035 per year or £25,023 over 15 years.

A sober estimate of the financial benefits to society of a key worker is £1,381 per year, or £16,981 over 15 years.

The cost of providing short break and key worker services exceeds their financial benefit. This suggests that the economic case alone is not sufficient to justify investment.

Implications

For both short break and key worker services, financial costs are greater than financial benefits. This suggests that the economic case alone is not sufficient to justify investment.

But financial savings are just one potential benefit of services for disabled children. There are other non-economic benefits, such as the happiness of the family, which we have not measured.

Moreover, we know that living with a disabled child affects all families differently. For some, the impact is shattering; for others, it is not. The conclusion of the analysis emphasises that targeting resources is most cost effective.

This report highlights the lack of data on the costs and outcomes of services for disabled children. Improving understanding through research is a priority in this area.

The report also includes a supplementary note which attempts to quantify the financial costs and benefits of services from targeting resources at children at risk of going into residential placements (see Appendix 8).



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Introduction

This report quantifies the financial costs and benefits of supporting disabled children and their families. It focuses on two services: short breaks and key workers. It presents the cost of these services and calculates the savings to society.

This report has been written to contribute to the HM Treasury and the Department for Education and Skills review of services for disabled children. It has been undertaken in the knowledge that bringing up a disabled child is hard, but is written without bias. New Philanthropy Capital (NPC) is happy to make any part of this paper available for further scrutiny.

Motivation

Resources for disabled children are limited so it is important that they are well spent. But understanding of the economics of services for disabled children is poor and there are few detailed studies of costs and benefits. This hampers effective decision-making.

This report is intended to inform the 2007 Comprehensive Spending Review. Throughout, calculations are laid out for the reader to inspect. It builds on NPC's previous publication on disabled children, *Ordinary Lives*.¹ More background information on policy and the role of charities can be found in that report.

Possibilities and limitations

This report aims to reveal as much as possible within the limits of the data available. It draws together a variety of sources to estimate the overall financial costs and benefits of short break and key worker services.

Data collected on disabled children and their families is limited, both in rigour and scope. Any analysis in this field is therefore imperfect. However, in all calculations we are conservative in the way that we apply data. This allows us to be confident that our estimates are robust. Importantly, we do not over-estimate benefits. Our estimates are as near as we can get to the true costs to society given the available data.

The whole cost?

We recognise that financial savings are just one potential benefit of services for disabled children. There are other non-economic benefits, such as the happiness of the family, which we do not currently have the tools to measure.

As such, the results of the analysis in this paper are not the end of any decision-making process. If the analysis shows that services imply an overall net financial cost to society, this should not necessarily be interpreted as reflecting badly on that service. (Similarly, if the analysis implies a financial benefit, this should not be taken as an immediate endorsement.)

Method and presentation

Finding data

The report draws on a wide range of published and unpublished sources. These included academic studies, government statistics, charity surveys and local authority evaluations. No primary data was collected.

We conducted a search of academic journals, using databases such as Web of Science and IngentaConnect.^{2,3} In addition, we contacted over 60 experts in the field including academics, independent consultants, civil servants and voluntary sector professionals. We interviewed these experts to identify other sources and placed a request for data in Interconnections Electronic Bulletin.⁴ A full list of contributors is included at the end of the report.

Where there was no direct evidence relating to disabled children and their families, we searched for proxies to enable us to get as close as possible to the true costs (eg, using data on the mothers of disabled children as a substitute for all primary carers of disabled children). Where appropriate, we also sought evidence from international sources.

We recognise that financial savings are just one potential benefit of services for disabled children.

Presenting data

The data collected are combined to estimate the costs and benefits of short break and key worker services. To link the data together, we have to make some assumptions. Throughout, we are clear about what these assumptions are. We use data conservatively so as not to over-estimate the benefits of services. All calculations are explained within the text.

Costs and benefits are presented for the 'average' disabled child. For example, a residential school costs £116,255 per child per year.⁵ However, as only 2% of disabled children attend residential schools the cost per average disabled child is £2,325 per year.

At the end of the report, we present the costs of short break and key worker services together with a sober and high-end estimate of the financial benefits of each service. Costs are presented as an annual cost and a total cost accrued over 15 years. We also present a division of the costs in terms of those that fall on the family (eg, parents' lost earnings), those that fall on employers (eg, parents' sick pay) and those that fall on the government (eg, residential care for the child).

References

Throughout the report we include references to all the sources used. In the main text, we refer to the bibliography in a standard format (ie, ⁵⁴). In the sections where we explain our calculations and more detail is required, we refer to tables in the Appendices using a different referencing system (ie, [54]). All of the sources referenced in the Appendices are also listed in the bibliography.

Technical points

We present a value for the costs and benefits of services over one year and 15 years. Fifteen years represents the assumed time period that a disabled child will live with his or her parents, beginning at age three when the child's needs start to diverge from other children (eg, the child cannot walk and becomes too heavy to lift) and ending at age 18 when the child becomes eligible for adult services.

Costs are presented in 2005/2006 prices. Each data points from the past are converted into 2005/2006 using the Office for National Statistics GDP deflator.⁶ Future costs are discounted using a real interest rate of 3%. Calculations assume that the child is age three in 2005.

Some totals may appear incorrect due to rounding. More detailed calculations are available separately on request.

Structure of this report

The first section reviews what we know about disabled children living in the UK. It describes an 'average' family of a disabled child. This provides a benchmark for subsequent calculations.

The second section provides unit costs for short breaks and key workers. It describes the outcomes of each service.

The third section links the outcomes of short break and key worker services with the financial benefits they imply. The 'total preventable costs' associated with living with a disabled child are determined relative to an average family.

The fourth section compares the financial costs and benefits of short break and key worker services. By varying the assumptions used, we present a sober and high-end estimate of the overall benefit of the services.

The fifth section concludes by discussing the implications of the findings.



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32% of families supporting a disabled child have no one working for more than 16 hours per week, compared with 16% of other families.

This section reviews what we know about disabled children living in the UK. It describes an ‘average’ family of a disabled child. This provides a benchmark for our subsequent calculations.

Number of disabled children

The Disability Discrimination Act (1995) defines disability as ‘a physical or mental impairment which has a substantial and long-term adverse effect on the ability to carry out normal day-to-day activities.’ This includes complex health needs, learning disability, autistic spectrum disorders, sensory impairment, physical impairment and emotional and behavioural disorders. Using this definition, the Department for Work and Pensions (DWP) estimates there are 700,000 disabled children in Britain.^{7, 8} The DWP’s figures also show that 121,700 children in the UK (or 17% of all disabled children) receive the higher rate for the Care Component of the Disability Living Allowance.⁹ This is a reasonable proxy for the number of severely disabled children. Appendix 1 provides details of all recent sources of estimates of the number of disabled children.

Place of residence

A small but significant minority of disabled children—around 15,500 or two percent—live in residential or foster placements outside their family home, predominantly paid for by social services.¹⁰⁻¹² The majority of these are boys of secondary school age with emotional, social and behavioural disorders (ESBD).¹⁰ Placements occur when the family can no longer cope with looking after the disabled child, perhaps due to stress on parents or if the child develops behaviour that the family cannot manage.^{10, 13, 14} This stress is compounded if there is a lack of services in the local area.¹⁵ Of the children in placements outside the home, 3,900 are in foster care; 2,100 are in children’s homes; 6,100 board in state-maintained schools; and 3,400 board in independent schools.^{10, 12} An additional 2,700 children have spent over six months in NHS hospitals.¹⁰ In 2006, the average

weekly cost per place for a foster care placement was £486.⁵ The average weekly cost of a residential care home was £2,236.⁵

The remaining 97 to 98% of disabled children live at home with their families.¹¹

Family structure

Thirty two percent of disabled children live in lone parent families, compared to 22% of other children.¹⁶ Whilst this suggests a link between living with a disabled child and parental separation, evidence from other sources is mixed. Debate centres on whether a disabled child brings the family closer together or puts impossible strain on relationships.

Anecdotal evidence paints a picture of a stressful home life, enormous strain on the family unit, eventually leading to breakdown.^{1, 17} A survey by the UK charity Contact a Family implicates the stress of bringing up a disabled child in 9% of separations.¹⁸ The notion of ‘breaking point’ has also been the subject of a recent campaign by Mencap.¹⁹

However, academic opinion on family breakdown is divided. In the UK, no studies have established a causal link with bringing up a disabled child. A study of children in the UK with low birth weight (which is known to be linked with risk of disability) reported no significant difference between rates of separation for parents of disabled children and parents of other children.²⁰

In the US, where a number of large-scale studies have been completed, the evidence is mixed. One study, based on a sample of 9,000 families, reported that for mothers married at the time of birth, the presence of a disabled child was associated with a four percentage point reduction in the likelihood of being married.²¹ A second study, with a sample half the size, reported that 12-18 months after birth, having a disabled child decreased in the probability that parents live together by an even larger margin of ten percentage points.²² Elsewhere, a study suggests that the age of the child is an important factor in marriage breakdown.

A survey of 10,000 disabled children between birth and nine showed that the difference in rates of divorce were only significant between ages six and nine.²³ But other US studies report no link with either marital quality or marital stability.^{24, 25} Possibly the best designed study, based on a sample of 7,000 individuals followed from after they left school found no evidence of differences between separation rates among families.²⁵

Two literature reviews on the subject have concluded that the evidence to support a difference between rates of separation is mixed, but if there is a positive link then it is likely to be small, in the region of a few percentage points (perhaps 1-5%).^{26, 27} Even less certain is the cause of this link. Is separation caused by stress on the family, or is it linked to other factors, such as poverty or other demographic differences? Interpreting the results of all these studies is problematic because none satisfactorily controlled for all of the relevant factors. Moreover, we have to be cautious about interpreting US data because of social and cultural differences, particularly the big gap between divorce rates in White and Black couples, which may not apply in the UK.²¹ This means that we should be cautious when calculating any benefits relating to family breakdown.

Family income

Employment

The demands of caring for a disabled child often mean that one parent, usually the mother, does not work. Eighty-four percent of mothers of disabled children do not work, 13% manage part-time work and 3% are in full-time work.²⁸ This compares with 39%, 39% and 22% of all mothers.

Thirty-two percent of families supporting a disabled child have no one working for more than 16 hours per week, compared with 16% of other families.¹⁶ In a study of the financial impact on families, the majority of mothers reported that they were unable to return to paid employment because of the need to care for their child.²⁹

As a consequence, in 2000, households with disabled children had an average income of £251 per week, compared to £303 for other families.¹⁶

Benefits

Families receive benefits and tax credits from the government to acknowledge the greater costs of bringing up a disabled child. Benefits include the Disability Living Allowance, Carers Allowance and Disability Facilities Grant.³⁰ For the purposes of calculating costs and benefits to society, benefit payments are ignored. This is because they represent a transfer payment from one part of society (government) to another (families) and therefore have a net value of zero.

Family expenditure

The day-to-day costs to the family for a disabled child are three times the cost of a non-disabled child. A study in 1998 for the Joseph Rowntree Foundation calculated that the minimum essential budget required to bring up a disabled child was £7,355 per year, compared with £2,100 for other children.³¹

Poverty, debt and living standards

High day-to-day costs compounded by low income mean that families with disabled children are four times more likely to live in poverty.^{16, 28} Data from the Department for Work and Pensions Family and Children Study showed that 31% of families with disabled children report debt, compared to 18% of other families.¹⁶ However, a survey commissioned by the Department for Trade and Industry in 2002 gave much higher figures of 84% and 47% respectively.³²

Families of disabled children are around twice as likely than other families not to be able to afford five or more 'everyday items'.¹⁶ Forty percent of respondents in a recent survey of families of disabled children reported problems with cold, damp and poor repair in their homes.³³

Families with disabled children are four times more likely to live in poverty.



Health

Ill health is thought to be more prevalent among families of disabled children than other families. In particular, stress-related illnesses such as depression and anxiety are common.³⁴⁻³⁶ In general, caring is known to be a stressful and isolating experience.³⁶⁻³⁹ Among carers of children under 16, 32% report a significant level of neurotic symptoms compared to 15% in the general population.^{36, 40} Most people with low-level mental illnesses do not get specialist care. It is thought that more than 80% of all mental health patients go no further than their GP for treatment.⁴¹

A number of studies report that the brothers and sisters of disabled children are more likely to experience behavioural and emotional problems.⁴²⁻⁴⁵ Anecdotal evidence suggests that three out of every four siblings of disabled children exhibit behavioural problems.⁴⁶ A more conservative estimate is that siblings of disabled children have a two-fold increase in behavioural and emotional disorders.⁴⁵

An ordinary life?

The consequence of having a disabled child is that the lives of families become very different. This causes stress and anxiety, which in turn can lead to other problems. These problems imply costs, both financial and non-financial.

Short break and key worker services are intended to reduce these costs and enable children and families to live 'ordinary lives'.



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Costs of short break and key worker services 2

This section outlines the calculation of unit costs for short breaks and key workers. It describes the outcomes of each service.

Short breaks

A break from caring is the most frequently reported need of families with disabled children.¹⁸ Short breaks relieve the strain on the family and give disabled children the opportunity to gain new experiences outside the family home.⁴⁷

Short breaks fall into a number of categories including family-based ‘shared care’, residential care, sitting services and befriending.⁴⁸ They include day, evening, overnight and weekend activities and may take place in the child’s own home, the home of an approved carer, or any other community setting. It is estimated that around 9,194, or 1.3% of all families of disabled children, receive short breaks.^{48, 49} Local authority figures suggest that anywhere between one and ten per cent of disabled children receive short breaks from social services.¹

All short breaks are provided by approved carers. Carers must be trained, approved and supported throughout their participation in the scheme by a social worker or scheme manager.¹⁷ Below we consider the unit cost of **shared care schemes using volunteer carers**. We also collected information on the costs of other types of short break, although we do not go into detail in this report. All this information is contained in Appendix 2.

Here we use a ‘bottom up’ approach to calculating the unit cost of short break services.⁵⁰ We consider the individual elements of the cost per carer and then calculate the costs per child.

- 1 The Fostering Network, a charity that represents everyone in the UK with a personal or professional involvement in fostering, gives a figure for the annual overhead costs of £13,416 per carer [9]. This comprises 14 separate elements, including social worker, management, administration, recruitment, approval and review costs [9]. Subtracting overheads that do not apply to short break carers (son and daughter support, educational support and support workers) reduces this to £10,410 [14]. This is based on one social worker managing a caseload of ten foster carers. It is calculated based on an annual turnover of carers of 15% [9].
- 2 Information provided by the Shared Care Network, a charity representing family-based short break schemes for disabled children in England, suggests that social workers manage a caseload of 20 short break carers [13]. This reduces overhead costs per carer to £5,205. Short break carers receive, on average, 14 hours of training before they are approved [8]. The Fostering Network estimate that training costs £11.43 per carer per hour [9]. Therefore, the total cost of training per carer is £160. Total overhead costs per carer are £5,365.
- 3 Carers care for on average 1.3 children [8].
- 4 Carers are paid, on average £44 for each overnight/24 hour period [8].
- 5 We assume that children require an average of one day’s break per week, plus one week per year holiday—a total of 57 days per year.

Paragraph:	1	2	3	4	5				
Cost of Short Breaks	=	(Overheads per carer	÷	Children per carer)	+	(Wage per day	×	Nights per year)	
	=	(£5,365	÷	1.3)	+	(£44	×	57)	=
									£6,635 per year per disabled child

Evidence shows that short breaks reduce stress on families.

Other sources

Surveys of the costs of short break services present much lower unit costs. A survey of 13 councils in South West England in 2003 reported a cost per night of £60, or an equivalent of £3,420 per annum for 57 nights [10]. Other estimates range between £37 and £284 per night [11,16-19]. It is our opinion that many of these do not properly account for overheads so we stick with our estimate of £6,635 per year.

Appendix 2 lists all the data collected on the costs of short break services.

Outcomes of service

There is limited evidence of the outcomes of short breaks. Most of the literature focuses on the desire for breaks, characteristics of service users and the different models, rather than what they achieve. Our review of the existing literature showed that:

Short breaks reduce the stress on parents (in particular mothers).

Two recent studies found statistically significant effects on reducing parental stress before and after short breaks [20,21]. This was corroborated by older studies [24,25,28]. There was also some evidence of contrary findings, where short breaks increased stress levels, but this was not the main focus of the report, and problems in the method used may have meant that observed changes were caused by other

factors [23]. Two recent literature reviews on the benefits of short breaks contradict each other. A review of breaks for carers of all disabled people in 1999 showed little evidence for positive effects [26]. A separate review of short breaks for carers of disabled children in 2001 revealed a general consensus in research that services are associated with a reduction in stress, particularly in mothers [22]. It is our view that the evidence for reductions in stress outweighs those sources that report little or no effect.

Short breaks reduce the need for out of home placements.

One study in the US found that short break care reduced out of home placements (for example hospital or residential placements) by more than 50%, although the sample size was quite small [20]. Anecdotal evidence from local authorities in the UK and the US also suggests a reduction [14,21].

Short breaks are beneficial for the child.

There is qualitative and anecdotal evidence showing that short breaks are enjoyed by children and can enable the families to become more included in their community.⁴⁷

Appendix 3 describes the empirical studies we found on the effectiveness of short break services.

Key workers

A recent Audit Commission report found that families with disabled children have to struggle through a maze of services to gain access to even basic support.⁵¹ Key working is a way of managing the package of support available and ensuring families access the services to which they are entitled.

Key workers are named individuals who act as a single point of contact with multiple services. They are informed individuals who enable families to better navigate the system.⁵² The Care Coordination Network, a charity that promotes and supports care key working for disabled children in the UK, lists 76 services on its website.⁵² Based on an average of roughly 100 families per service, around 7,000 to 8,000 families receive key working services.⁵³

Calculating the unit cost

Here we use a 'top down' approach to calculating the unit cost of key worker services, based on data from a recent study.⁵⁰

6 Based on a 2006 study for the Department for Education and Skills, the average cost of a key worker scheme per family per year is **£2,035** [29]. The unit cost for each scheme was calculated by dividing the total budget for the scheme by the number of families supported. The cost given here is the mean figure for 12 established schemes.

Paragraph:	6	
Cost of Key Workers	=	Average cost of key worker scheme per family across 12 schemes run by the Care Coordination Network = £2,035 per year per disabled child

Components of cost

Most of this cost is the salary of the key worker, with the remainder being the costs of management, administration, overheads and travel. The 2006 Care Coordination Network survey reports that a dedicated key

worker can support 30 families [32]. On average, key workers visit families once a month and speak every three weeks [32]. The mean annual amount of contact per family is just under 15 hours.

The mean amount of time families had used the services was three years and four months [32]. Greater contact between families and key workers occurs at times of transition or during medical or family changes, for example when the child starts school.

Appendix 4 lists all the data collected on the costs of key worker services.

Other issues

One obvious advantage of key workers is that they increase government efficiency by providing a single point of contact for families and reducing the number of meetings. Despite this widely accepted justification, there are no studies that attempt to quantify this benefit. We take a conservative approach to estimating the benefits of key worker services by not including these in our calculation.

Conversely, key workers also imply higher costs to government by increasing take up of benefits and use of services. As previously noted, benefit payments are not included in calculations of cost to society as they represent a transfer. Since other services are simply those to which families have a statutory entitlement, we exclude these from our calculation.

Outcomes

As with short break services, there is little data on the benefits of key workers. Our review of the existing literature shows that:

Key workers reduce stress for parents

Parents with key workers consistently report greater 'peace of mind' and reduced stress [32,33,41,43]. Families report feeling less isolated [34]. There is some evidence that key workers improve emotional health, quality of life and coping [32,36]. One study on a small number of families in the UK showed a statistically significant effect on the emotional health of parents [36].

Key workers mean that families make better use of other services

Key working increases the use of services [32-34]. There are plenty of anecdotal reports of these benefits, listed in Appendix 5, but no quantitative data.

Key workers reduce the number of sick days taken by parents and reduce children's admissions to hospital

An evaluation of the US 'medical home' model (which combines professional and

family-centred care) showed statistically significant effects on reducing the number of sick days taken by parents and reducing the time spent by disabled children in hospital [42]. In a sample of 150 families, the number of parents missing 20 working days in a year fell from 26% to 14%. Admissions to hospital fell from 58% to 43%.

Appendix 5 describes the empirical studies we found on the effectiveness of short break services.



Photograph supplied by Shared Care Network.

From outcomes to financial benefits

3

This section links the outcomes of short breaks and key workers with the financial benefits they imply. Financial benefits are determined relative to the ‘average’ disabled child.

What we know

Hard evidence on the outcomes of short break and key worker services is sparse.^{54, 55} We know that they reduce stress among families but there are no studies documenting the subsequent impact on the family. This means that we cannot directly calculate the financial benefits of each service.

Although we lack quantitative evidence, we know that these services have benefits. There is a wealth of positive anecdotal evidence from families.^{19, 55, 56} Studies in other areas of social research link the effects of stress to unemployment, underemployment, physical health and education.^{41, 57} For example, stress on parents may result in lost work days due to ill health. This has a cost to the family (from reduced income) and to the government (from lost tax receipts).

Assumptions

Given the lack of direct evidence, to calculate the financial benefits of services we have to make some assumptions. Combining anecdotal evidence and the evidence from other areas of social study (eg, the literature on mental health), we have a good idea about which costs associated with disabled children and their families could be prevented. If we can then quantify these ‘preventable costs’ they can then help us to determine the benefits of short break and key worker services.

To determine the preventable costs, we make the following assumptions:

- reducing stress increases parents’ ability to work;
- reducing stress decreases the number of sick days employed parents take;

- reducing stress reduces parents’ demand on the health service;
- reducing stress reduces the probability that the siblings of disabled children will develop emotional and behavioural problems;
- reducing stress reduces the need for parents to seek residential or foster care for their child; and
- reducing stress reduces the probability of family breakdown.

‘Preventable costs’ are therefore the costs that could be saved if we could remove all the stress of caring for a disabled child.

Calculating preventable costs

Based on these assumptions, we can determine the total preventable costs associated with caring for a disabled child. Preventable costs have six distinct elements. These are:

- the cost to the family from parents not being in work;
- the cost to employers from parents’ stress;
- the cost to the health service from parents’ stress;
- the cost to schools from educating siblings with emotional and behavioural difficulties;
- the cost to social and educational services of caring for a disabled child outside the family home; and
- the cost to the family of separation and marital breakdown.

The remainder of this section is concerned with calculating these costs. We address each in turn, explaining our calculations step by step. In each case, we tend towards conservative estimates of the costs. All costs are presented as an average per disabled child per year. Sources used in these calculations can be found in Appendix 6.

84% of mothers of disabled children are unemployed compared to 39% of mothers of non-disabled children.

Family model

As a starting point, we need to understand the 'average' family of a disabled child.

1 Ninety-eight percent of disabled children live at home. Two percent live in residential care homes [47]. Sixty-six percent live in two-parent families and 32% live in single-parent families [46].

2 This means that there are on average $(0.66 \times 2) + (0.32 \times 1) = 1.64$ parents per disabled child.

3 There are approximately 1.8 children in the average UK family so we assume that the average disabled child has 0.8 siblings [51].

The cost to the family from parents not being in work

One or more parent being out of work means that the family incurs a cost associated with lost earnings.

4 We consider only lost earnings from the primary carers of disabled children. We take data about mothers as our proxy as there is no equivalent data for carers in general.

5 Eighty-four percent of mothers with disabled children are unemployed compared with 39% of mothers of non-disabled children [48]. So, we estimate that an 45% of primary carers of disabled children would work if given the opportunity. This is similar to the 85% of mothers of disabled children in a recent survey that said they would like to work [49].

6 According to a study of the 1985 General Household Survey, a typical mother caring for a disabled child who is employed, will work approximately 18 hours per week [67]. We think that this is a reasonable expectation for the primary carer of disabled children, given that we know most mothers would like to work. We think it is unreasonable to expect that they would work a full working week.

7 We make the assumption that carers would earn the median wage for a female part-time worker of £7 per hour [50].

8 It is standard practice to add 25% to earnings to account for non-wage labour costs (for example, employer National Insurance and pension contributions). For female part-time workers, this is £1.75 per hour.

Paragraph:	1	5	6	7	8								
Cost from Lost Earnings	Primary carers per child	x	Percentage of potential workers	x	Hours worked per week	x	(Average female part-time wage	+	Non-wage labour costs)	x	Weeks in a year	=	£3,612 per year per disabled child
	= 0.98	x	45%	x	18	x	(£7	+	£1.75)	x	52	=	

The cost to employers from parents' stress

Ill health, caused by stress, increases the number of work days parents miss. This has a cost to the employer associated with sick pay and lost productivity.

9 The parents of disabled children consistently show higher than average stress levels. We assume that 100% suffer from stress. It is estimated that as many as 20% of the general population suffer from stress [66]. To account for this, we include only 80% of the costs of stress.

10 Sick days are counted for one parent only, for the 66% of families where there are two parents present [46].

Data from the Families and Children Study shows that 84% of two-parent families supporting a child at risk of disability had at least one parent working for more than 16 hours a week [46]. We therefore assume that there are 0.56 (0.84 x 0.66) wage earners per disabled child.

11 It is estimated that someone suffering from stress will take an extra eight days of sick leave per year [69].

12 The amount lost to business per sick day is calculated from the average weekly wage in 2006 of £537.30 to be £107.46 [50].

Paragraph:	9	10	11	12						
Cost of Sick days	=	Percentage of extra stressed people	x	Average number of wage earners per child	x	Number of sick days taken per stressed person per year	x	Average daily wage	=	£381 per year per disabled child
	=	80%	x	0.56	x	8	x	£107.46	=	£381 per year per disabled child

The cost to the health service from parents' stress

Ill health, caused by stress, increases the demand parents make on the health service. This has a cost to the public purse.

13 Increased levels of stress doubles the chances of illness or injury [65]. Since most patients suffering stress-related

illnesses usually do not receive any specialist care, we assume that this translates into a doubling of GP visits for each parent, or an extra four visits per year [70].

14 From Personal Social Services Research Unit data, the cost of a visit to a GP with a full prescription inflated to 2005/2006 prices is £54.41 [12].

Paragraph:	2	9	13	14						
Cost of GP visits	=	Number of parents per disabled child	x	Percentage of extra stressed people	x	Number of extra visits to the GP	x	Cost of a GP visit with prescription	=	£286 per year per disabled child
	=	1.64	x	80%	x	4	x	£54.41	=	£286 per year per disabled child

Being the sibling of a disabled child doubles the chance of having an emotional, behavioural or social disorder.

The cost to schools from educating siblings with emotional and behavioural difficulties

Children with emotional and behavioural difficulties place a greater demand on the education system. This has a cost to the school associated with employing more teaching resources.

15 Having a sibling with a disability increases the risk of having an emotional, behavioural or social disorder (EBSD) [54,55,58]. The most conservative estimate is that being the sibling of a disabled child doubles the chance of having an EBSD [62].

16 We use Department for Education and Skills figures to estimate that the baseline rate of EBSD is 4% [60]. This means that an extra 4% of siblings of disabled children have an EBSD.

17 Ofsted estimates that the extra cost of educating a child with an EBSD is £1,078 in a mainstream primary school and £3,235 in a mainstream secondary school [52].

Paragraph:	3		15	16		17	
Cost of primary school for siblings with EBSD	=	Number of siblings per disabled child	x	Percentage of extra siblings with EBSD	x	Extra cost to a primary school per year	
	=	0.8	x	4%	x	£1,078	= £35 per year per disabled child

Paragraph:	3		15	16		17	
Cost of secondary school for siblings with EBSD	=	Number of siblings per disabled child	x	Percentage of extra siblings with EBSD	x	Extra cost to a secondary school per year	
	=	0.8	x	4%	x	£3,234	= £104 per year per disabled child

The cost of caring for a disabled child outside the family home

Stress on families is a cause of children going into residential placements, either in the care of social services or to a residential educational establishment. Disabled children looked after outside the family home place a high cost on education and social services.

18 There are approximately 11,600 disabled children in educational and social residential placements (2,100 in children's homes and 9,500 in residential schools) [47]. This corresponds to 1.7% of all disabled children.

19 We recognise that not all children in residential placements could be cared for at home. However, there is evidence that placements are made due to stress on the family, compounded by a lack of local services and support [85,86]. This is corroborated by the twenty-fold variation in the number of out-of-authority placements made by local authorities, suggesting that in some authorities support for families is better than in others [72]. Data from the 2003 Children in Need survey shows that 1,110 out of 2,110 children, or 53% of children in residential placements, have multiple

disabilities [48]. We take 'multiple disabilities' as a proxy for severe disability and assume that this group cannot be cared for at home. Therefore, 47% residential placements could be prevented.

20 The costs of residential care vary substantially, depending on the provider and the needs of the child, e.g. [17]. For our estimate we use a unit cost per week of £2,236 for residential care taken from the Personal Social Services Research Unit's Unit Costs of Health and Social Care [12].

21 There are approximately 3,900 disabled children in foster care placements [74]. This corresponds to 0.6% of all disabled children.

22 As in paragraph 19 above, we recognise that not all children in foster care could be cared for at home. We assume the same proportion of foster care placements as residential placements could be prevented (47%).

23 We use the unit cost per week of £486 for foster care taken from the Personal Social Services Research Unit's Unit Costs of Health and Social Care [12].

Paragraph:	18	19	20						
Cost of Residential Care	=	Percentage of disabled children in residential care	x	Proportion of children in residential placements that are preventable	x	Cost per place per week	x	Weeks in a year	
	=	1.7%	x	47%	x	£2,236	x	52	£913 per year = per disabled child

Paragraph:	21	22	23						
Cost of Foster Care	=	Percentage of disabled children in foster care	x	Percentage foster care placements that are preventable	x	Cost per place per week	x	Weeks in a year	
	=	0.6%	x	47%	x	£486	x	52	£67 per year = per disabled child

The cost to the family of separation and marital breakdown

Stress on families caused by caring for a disabled child may be a cause of family breakdown. The process of separation, and the resulting two households rather than one, places a high cost on families. Many of the other costs which may be associated with family breakdown (such as the need for foster care and the emotional and behavioural development of other children) are already accounted for above.

24 Evidence suggests that married couples with disabled children aged between birth and 18, have a slightly greater chance of separating than other couples with children [76-80]. We use a low to middle-range estimate of around 4% [80]. This equates to an average of 0.25% greater chance of divorce per year per child. (This has been calculated assuming the chance of separation remains constant during the period.)

25 Parents pay an average of £927 in legal fees for separation and £2,110 to set up a new home [86]. This is a total one off cost of £3,037 per family.

26 One parent moves out of the family home and rents a one bedroom flat at a cost of £710 per month, or £8,520 per year [85]. According to the Office for National Statistics, the average spending of households on council tax, bills and other local charges is £23 per week, or £1,196 per year [87]. This is a total annual ongoing cost of £9,716.

27 When calculating costs over 15 years, we assume that family breakdown occurs when the child is age seven, the average age for a child of divorcing parents [84].

Paragraph:	24		25	
One-off cost of separation	=	Annual probability that parents will separate due to having a disabled child	x	Cost of legal fees and setting up new home
	=	0.25%	x	£3,037
				= £8 per year per disabled child

Paragraph:	24		26	
Ongoing cost of separation	=	Percentage of parents separated due to having a disabled child	x	Annual cost of renting a one bedroom flat, with bills
	=	4%	x	£9,716
				= £389 per year per disabled child

Total preventable costs

Adding together each of the elements of cost from the boxes in the section above gives the total preventable costs per disabled child. This corresponds to the amount it would be possible to save were the stress involved in caring for a disabled child entirely alleviated.

Table 1 summarises the breakdown of the total costs by the elements of cost. Costs are given per year and for 15 years, beginning in 2006. Table 2 shows the proportion of costs that fall on the family, employers and the government.

Table 1: Preventable costs by the type of cost

Cost	Preventable cost per year per disabled child	Preventable cost per disabled child over 15 years*	Proportion of cost
Lost earnings	£3,612	£44,410	65%
Sick days	£381	£4,688	7%
GP visits	£286	£3,511	5%
School costs for siblings with EBSD	£69**	£739***	1%
Residential care	£913	£11,227	16%
Foster Care	£67	£821	1%
Family breakdown – one-off costs	£8	£93	0.1%
Family breakdown – ongoing costs	£285****	£3,291 [§]	5%
TOTAL	£5,620	£68,781	100%

* Discounted using a real interest rate of 3%.

** This is an average cost of primary and secondary school.

*** Assuming the sibling is in primary school from 2006-2012 and in secondary school from 2013-2019.

**** This value is reduced to reflect that these costs do not start until the child is aged 7.

§ Assuming ongoing costs start at age 7.

Table 2: Preventable costs by bearer of cost

Bearer of cost*	Preventable cost per disabled child over 15 years*	Proportion of cost
Family	£45,642	68%
Employer	£4,688	7%
Government	£18,451	25%
TOTAL	£68,781	100%

* Costs to the family include lost earnings (minus income tax and National Insurance contributions) and family breakdown. Costs to the employer include lost sick days. Costs to the government include lost income tax and National Insurance, extra GP visits, schooling of siblings with EBSD and residential care.

Comparing costs and benefits

4

This section compares the financial costs and benefits of short break and key worker services. By varying the assumptions used, we present a sober and high-end estimate of the overall benefit of the services. These two estimates make different assumptions about costs that could be saved, based on different rates of success in reducing stress on the family.

Financial costs

Short break services cost £6,635 per disabled child per year.

Over 15 years, this costs **£81,584**

Key worker services cost £2,035 per disabled child per year.

Over 15 years, this costs **£25,023**

If provided together as a package, the services cost £8,670 per disabled child per year.

Over 15 years, this costs **£106,607**

Financial benefits

The financial benefits of services for disabled children in our model derive from their success in reducing stress on the family.

As described in the last section, the total preventable cost per disabled child per year is £5,724. Over 15 years, this amounts to £68,781.

This figure assumes that all of the costs associated with stress on the family are saved. In practice, saving all these costs is unrealistic: even the best services cannot expect a 100% success rate. It is likely that there will be considerable variability in the reductions in stress among families, even within the same service. Therefore, to get a more realistic estimate of average financial benefit, we need to consider the costs saved if only a proportion of stress was relieved.

Estimating benefits

Tables 3 and 4 summarise the financial benefits for services per year and over 15 years, given different success rates in reducing stress. The columns of the table allow us to vary between 100%, 80%, 60%, 40%, 20% and 0% of the maximum benefit for each element of cost.

We can use these tables to estimate the financial benefits of short break and key worker services. By varying the proportion of costs saved in each area, we can produce different estimates of financial benefit.



Photograph supplied by Merseyside Access to Play.

Table 3: Potential financial benefits of services per year, given different success rates

Cost	100%	80%	60%	40%	20%	0%
Lost earnings	£3,612	£2,889	£2,167	£1,445	£722	£ –
Sick days	£381	£305	£229	£153	£76	£ –
GP visits	£286	£228	£171	£114	£57	£ –
School costs for siblings with EBSD	£69	£55	£41	£28	£14	£ –
Residential care	£913	£730	£548	£365	£183	£ –
Foster care	£67	£53	£40	£27	£13	£ –
Family breakdown – one-off costs	£8	£6	£5	£3	£2	£ –
Family breakdown – ongoing costs	£285	£228	£171	£114	£57	£ –

Table 4: Potential financial benefits of services over 15 years, given different success rates

Cost	100%	80%	60%	40%	20%	0%
Lost earnings	£44,411	£35,529	£26,647	£17,764	£8,882	£ –
Sick days	£4,688	£3,751	£2,813	£1,875	£938	£ –
GP visits	£3,511	£2,809	£2,107	£1,405	£702	£ –
School costs for siblings with EBSD	£739	£591	£444	£296	£148	£ –
Residential care	£11,227	£8,981	£6,763	£4,491	£2,245	£ –
Foster care	£821	£656	£492	£328	£164	£ –
Family breakdown – one-off costs	£93	£75	£56	£37	£19	£ –
Family breakdown – ongoing costs	£3,291	£2,633	£1,974	£1,316	£658	£ –

Short break services

From the evidence presented in this report, we are confident in the success of short break services at reducing the stress on families.

Table 6 presents a sober and a high-end estimate of financial benefits, assuming different rates of success in reducing costs. Under sober estimates, we assume:

- forty percent of primary carers that do not work return to work part-time;
- sixty percent of extra sick days taken by parents of disabled children are prevented;
- sixty percent of GP appointments made by parents of disabled children are prevented;

- twenty percent of siblings of disabled children that would otherwise have developed EBSD do not;
- sixty percent of disabled children that would otherwise have gone into residential care do not;
- sixty percent of disabled children that would otherwise have gone into foster care do not; and
- twenty percent of families that would otherwise have separated do not.

These proportions represent our judgement of what can reasonably be expected from short break services. Under our high-end estimate, the proportions are higher (see below).

Table 5: Financial benefits of short break services (sober and high-end estimate)

Cost	Sober estimate			High-end estimate		
	Percentage	per year	over 15 years	Percentage	per year	over 15 years
Lost earnings	40%	£1,445	£17,764	60%	£2,167	£26,647
Sick days	60%	£229	£2,813	80%	£305	£3,751
GP visits	60%	£171	£2,107	80%	£228	£2,809
School costs for siblings with EBSD	20%	£14	£148	40%	£28	£296
Residential care	60%	£548	£6,736	80%	£730	£8,981
Foster care	60%	£40	£492	80%	£53	£656
Family breakdown – one-off costs	20%	£2	£19	40%	£3	£37
Family breakdown – ongoing costs	20%	£57	£658	40%	£114	£1,316
TOTAL		£2,505	£30,737		£3,629	£44,494

Financial benefits of short break services

Sober estimate: financial benefits are **£2,505 per year**
 financial benefits are **£30,737 over 15 years**

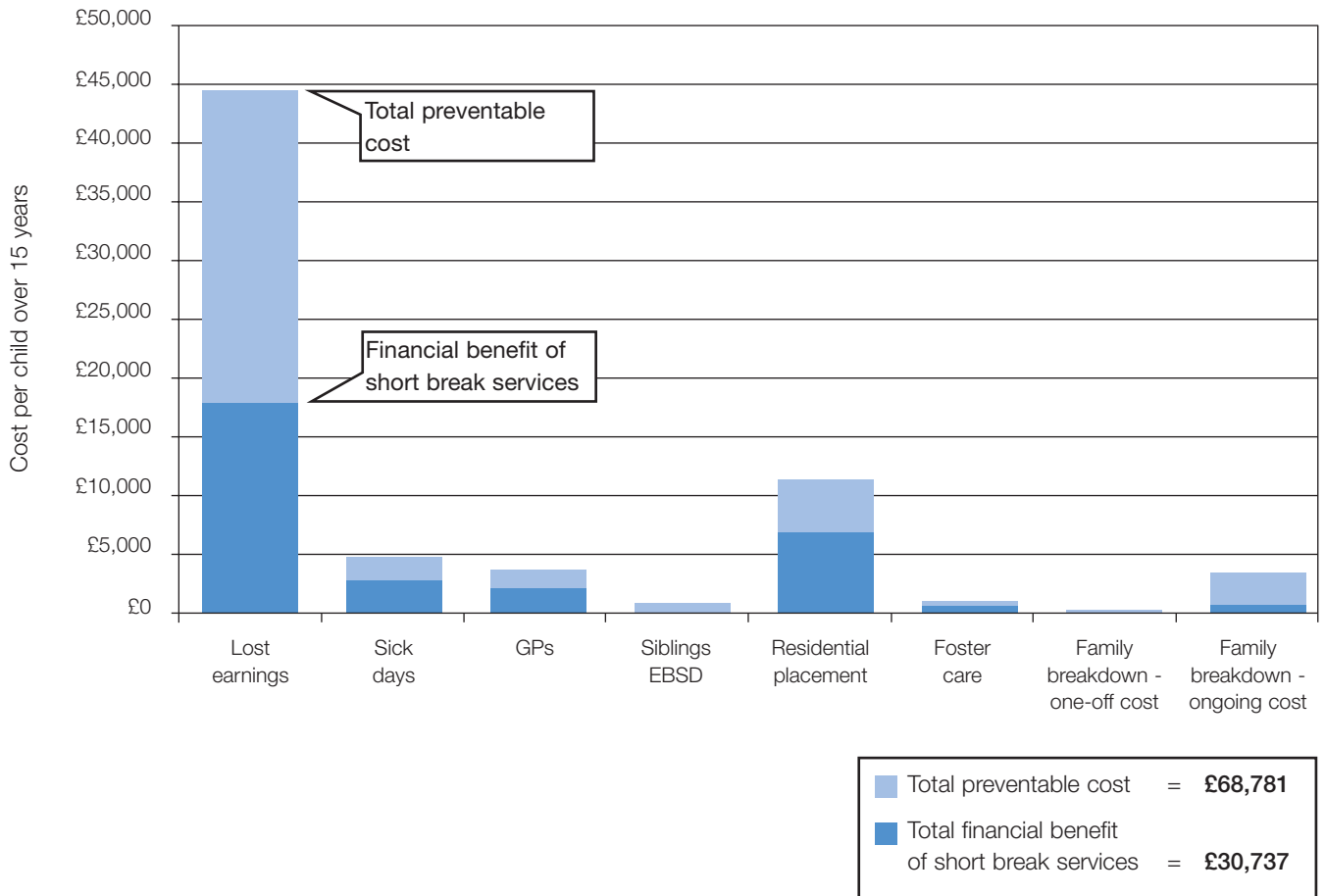
High-end estimate: financial benefits are **£3,629 per year**
 financial benefits are **£44,494 over 15 years**

Comparing preventable costs and financial benefits of short break services

Figure 1 compares the total preventable costs (contained in Table 1) and the financial benefits of short break services (contained in Table 5) over 15. The height of each bar indicates the total preventable cost and the

dark blue section of each bar indicates our estimate of the financial benefits. The figure indicates that the largest element of benefit comes from helping parents back into work. The second largest benefit comes from preventing residential placement.

Figure 1: A comparison of total preventable costs and financial benefits of short break services over 15 years



Photograph supplied by Merseyside Access to Play.

Key worker services

Based on the evidence for key worker services, we can be less confident in their success at reducing stress than with short break services.

Table 6 presents a sober and a high-end estimate of financial benefits, assuming different rates of success in reducing costs. Under sober estimates, we assume:

- twenty percent of primary carers that do not work return to work part-time;
- forty percent of extra sick days taken by parents of disabled children are prevented;
- forty percent of GP appointments made by parents of disabled children are prevented;

- there is no benefit to the siblings of disabled children;
- forty percent of disabled children that would otherwise have gone into residential care do not;
- forty percent of disabled children that would otherwise have gone into foster care do not; and
- no families that would otherwise have separated do not.

These proportions represent our judgement of what can reasonably be expected from key worker services. Under our high-end estimate, the proportions are higher (see below).

Table 6: Financial benefits of key worker services (sober and high-end estimate)

Cost	Sober estimate			High-end estimate		
	Percentage	per year	over 15 years	Percentage	per year	over 15 years
Lost earnings	20%	£722	£8,882	40%	£1,445	£17,764
Sick days	40%	£153	£1,875	60%	£229	£2,813
GP visits	40%	£114	£1,405	60%	£171	£2,107
School costs for siblings with EBSD	0%	£ –	£ –	20%	£14	£148
Residential care	40%	£365	£4,491	60%	£548	£6,736
Foster care	40%	£27	£328	60%	£40	£492
Family breakdown – one-off costs	0%	£ –	£ –	20%	£2	£19
Family breakdown – ongoing costs	0%	£ –	£ –	20%	£57	£658
TOTAL		£1,381	£16,981		£2,505	£30,737

Financial benefits of key worker services

Sober estimate: financial benefits are **£1,381 per year**
 financial benefits are **£16,981 over 15 years**

High-end estimate: financial benefits are **£2,505 per year**
 financial benefits are **£30,737 over 15 years**

Comparing preventable costs and financial benefits

Figure 2 compares the total preventable costs (contained in Table 1) and the financial benefits of key worker services (contained in Table 6) over 15 years. The height of each bar indicates the total preventable cost and

the dark blue section of each bar indicates our estimate of the financial benefits. The figure indicates that the largest element of benefit comes from helping parents back into work. The second largest benefit comes from preventing residential placement.

Figure 2: A comparison of total preventable costs and financial benefits of key worker services over 15 years

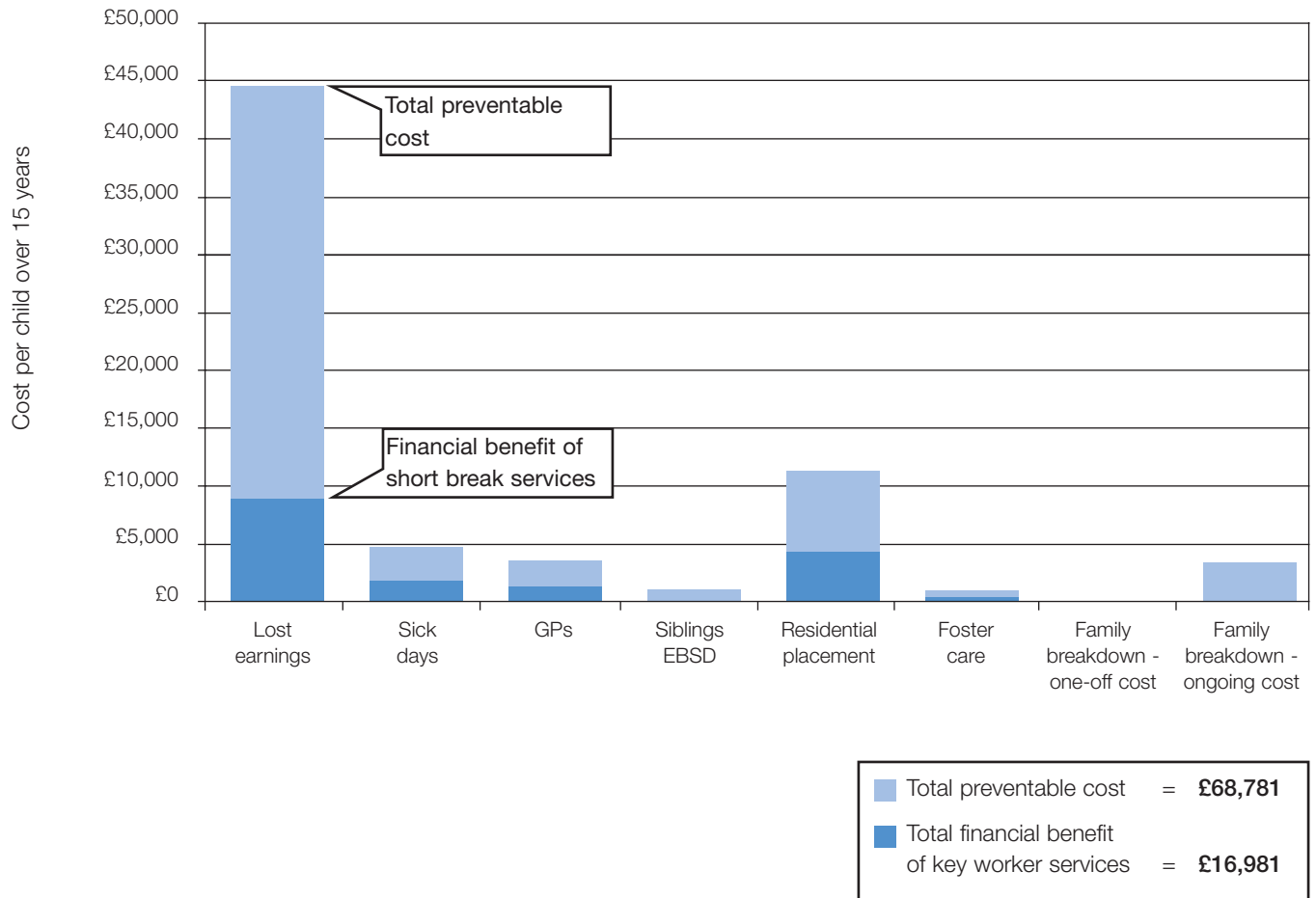


Table 7: Net financial benefits (costs) of services for disabled children

	Costs saved per average disabled child, per year	Costs saved for ALL disabled children, per year	Costs saved per average disabled child, over 15 years	Costs saved for ALL disabled children, over 15 years
Short break services	£(4,130)	£(2,891,000,000)	£(50,847)	£(35,593,000,000)
Key worker services	£(654)	£(458,000,000)	£(8,042)	£(5,629,000,000)

Net financial benefits

By subtracting the unit costs of each service from the financial benefits, we can determine whether there is a straightforward economic case for investing in services for all 700,000 disabled children. Table 7 shows the results of this calculation using our sober estimate of the financial benefits of each service.

The negative value for short break services indicates a net financial loss to society, of £50,847 per child over 15 years, or £35.6bn for all disabled children. The negative value for key worker services also indicates a net financial loss to society of £8,042 per child over 15 years, or £5.6bn for all disabled children.



Photograph supplied by Shared Care Network.

Comparing financial costs and financial benefits of both services

Figure 3 presents our estimates of the total preventable costs and the total financial benefits of each service over 15 years. The height of each bar indicates the total preventable cost and the dark blue section of each bar indicates the financial benefit of each service. The blue lines indicate the cost of providing each service.

For short break services, the cost of providing the service exceeds both the financial benefit and, perhaps more significantly, the total preventable cost. This implies that the financial costs of short

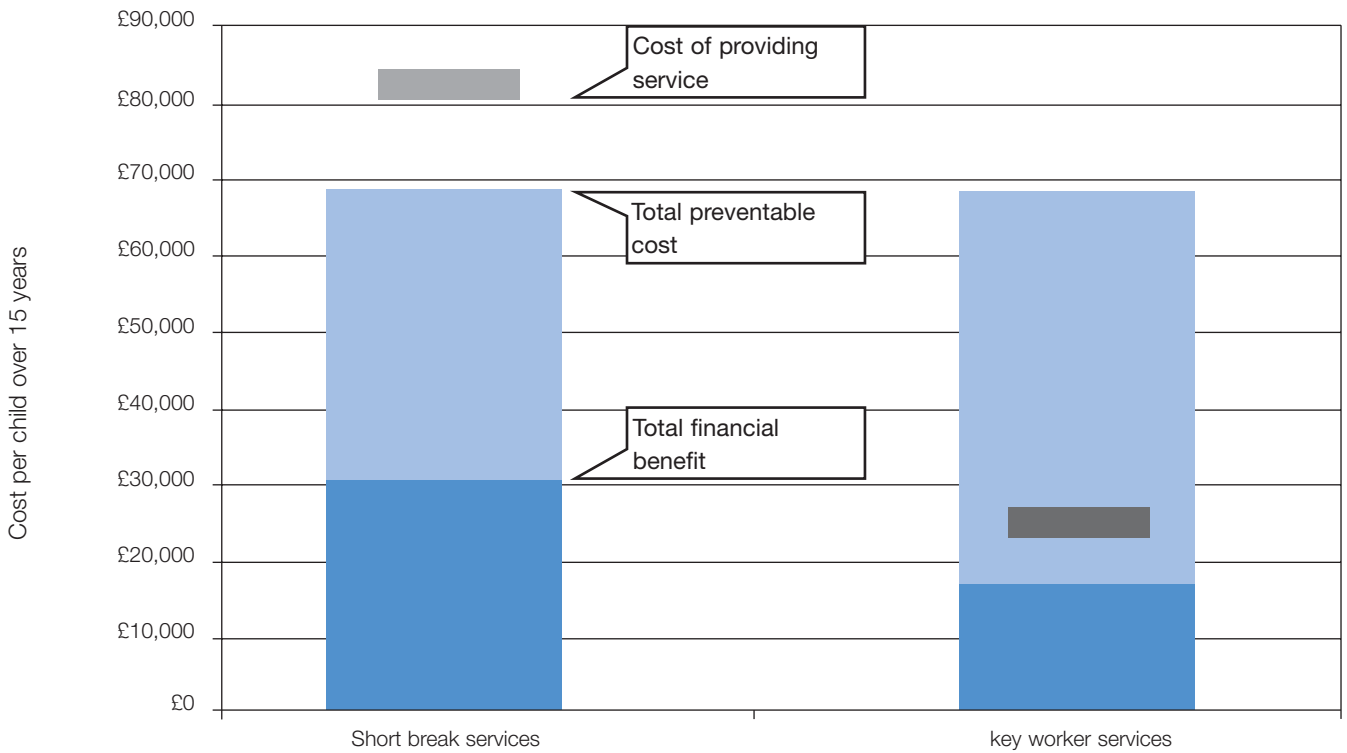
breaks will always exceed the benefits, even if they are one 100% successful at reducing the stress on families.

For key worker services, the cost of providing the service exceeds the financial benefit. However, it is less than the total preventable costs. In our estimates, key worker services save 25% of the total preventable cost. To match the cost of providing the services—or ‘break even’—they would need to save 37%, an increase of 12 percentage points.

We discuss the implications of these findings in the next section.

The cost of providing short break and key worker services exceeds their financial benefit.

Figure 3: A comparison of the costs and benefits of providing services over 15 years



Total preventable cost = £68,781			
■ Total financial benefit of short break services = £30,737	■ Total financial benefit of key worker services = £16,981		
■ Total cost of providing short break services = £81,584	■ Total cost of providing key worker services = £25,023		

Discussion and conclusions

5

The cost of short break services might be reduced by improving the retention of and offering incentives to carers to increase the number of children they look after.

Taken over the whole population of disabled children, this report suggests that the cost of providing short breaks is more than the financial benefit. Similarly, the cost of providing key worker services is more than the financial benefit. This suggests that there is not a straightforward economic case for investment in either service.

This is an interesting finding as it challenges the way we think about families and how we can support them. This comparison of costs moves us further towards understanding how resources should best be allocated to disabled children and their families.

Why are the costs of short break services more than the benefits they produce?

At an annual cost of £6,635, short break services are expensive. In comparison, the benefits of these services are relatively modest. The data suggest that although families with disabled children have tough lives, this does not automatically translate into high financial costs. Families are resilient and continue to live their lives, even though they face considerable challenges.¹ Stress and emotional turmoil are not always financially costly.

How can we make short breaks less expensive?

Recruitment, management and other overhead costs account for 62% of the total annual cost, whereas carer allowances account for only 38%. The largest proportion of these overheads is the support given by social workers, which accounts for 30%. One obvious suggestion is to look at ways of reducing overheads.

At present, the caseload of social workers who manage services is high, so reducing staff costs would be unrealistic. Similarly, some of the costs for essential items such as equipment and transport are unlikely to be changed.

One notable cost is in approving and reviewing short break carers, which takes up a large proportion of the social worker and management time. Short break carers have to go through the same process as full-time registered foster carers, and are governed by both fostering and domiciliary care regulations.⁴⁸ It is possible that costs may be reduced by streamlining this process and removing some of the elements that are less applicable to short break carers.

Given that it costs around £11,500 to recruit a carer, costs might also be reduced by improving the retention of and offering incentives to carers to increase the number of children they look after. At present, recruitment accounts for 10% of the costs of short breaks.

Why do key worker services appear more cost effective?

The simple answer is that they are cheaper to provide. At a cost of £2,035, key worker services are less than 40% of the cost of providing short breaks. Although the financial costs of key worker services still exceed the financial benefits, the difference is much less than with short breaks. Even though they are less successful at alleviating stress, their low cost ensures that they return a higher relative financial benefit.

Criticisms

This report is the first to estimate the costs and benefits of services for disabled children. By focusing on financial costs and benefits, it has taken what may be an unfamiliar approach to many people. For this reason, it will inevitably draw criticism. Below we address some possible objections.

The study uses unreliable data

There is a real lack of data on disabled children. Information on cost and outcomes of services is not routinely collected and there are few studies that try to untangle these questions. We do not claim that this study is perfect, but it uses what data is available as well as possible to produce an estimate of costs and benefits. Given better data, this

study could be extended and guarantee a greater degree of accuracy. However, given the limitations, we have done as much as we can to produce a reliable estimate and we are confident in the figures that we present.

The study underestimates the financial benefits of services

We admit that our analysis is more likely to underestimate the financial benefits of services than to overestimate them. Most important is that this study produces a reliable estimate of benefits in which we can have confidence. Therefore, we avoided any assumptions that would inflate benefits.

Our estimates are based on combining the data we collected with informed assumptions. Given this methodology, we tend to side with data that gives us a lower value of the benefits. For example, when discussing siblings we used an estimate of double the chances of EBSD.⁴⁵ Some evidence suggests that it is more than ten times this.⁴⁶ Second, there may be elements of cost for which we have not accounted. For example, when looking at the costs of healthcare, we only considered GP appointments and not any elements of secondary care.

The study ignores the non-financial benefits of services

In the introduction to this report, we recognised that financial savings are just one potential benefit of services for disabled children. There are other benefits, such as the happiness of the parents and child. We excluded these benefits because we do not have the tools to measure them.

The benchmark in health economics is the quality adjusted life year, or QALY. QALYs are a way of measuring the quality and quantity of life as a means of determining the benefit of a medical intervention. A year of perfect health is worth one QALY and a year of imperfect health is worth less than one. Given better data, it might be possible in future for researchers to use QALYs to assign a financial value to the health and stress levels of parents of disabled children. For now, we are left to consider whether the non-financial benefits of services outweigh the difference between financial costs and benefits.

By basing calculations on an ‘average’ family, the study ignores individual differences

At the outset we made it clear that this study dealt with an ‘average family’. Of course, within the population of families living with a disabled child, the costs and benefits will not be distributed evenly. It might be that one family incurs none of the costs we have talked about and another family incurs all of them. The advantage of defining an average family is that we can take into account all this variation.

A second point is that we are limited by the data available. In large part, this data deals in averages. In most cases, we are not able to distinguish between different disabilities and different social groups. But whatever differences there are between groups, it is true that there are generic challenges that all families living with a disabled child face.

Targeting resources

We know from anecdotal evidence that living with a disabled child affects all families differently.¹ For some, the impact is shattering; for others, it is not. Correspondingly, there will be some families that need services more and some families that need services less. This suggests that if the government is planning to increase services available to the families of disabled children, targeting of resources would be most efficient.

It may be that some groups of families would gain more than others from access to short break and key worker services, and therefore imply greater financial benefits. Any targeting would need to be backed up by good quantitative research. A supplement to this paper attempts to quantify the financial costs and benefits of services from targeting resources at children at risk of going into residential placements (see Appendix 8).

The fact is that many families hang their hopes on these services.

Final word

Examining financial costs and benefits is an essential part of evaluating services for disabled children.

But we must also remember that the human case for services is strong. Of the criticisms listed above, probably the most significant is the inability to account for the non-financial benefits. The fact is that many families hang their hopes on these services. Nevertheless, this report has demonstrated that helping children and families to live an ordinary life can be costly.

Finally, this report has highlighted the lack of data on the costs and outcomes of services for disabled children. Improving understanding through research should be a priority for government. We have applied our model of costs and benefits to short break and key worker services. There are other services for disabled children and their families that are not well understood, such as speech and language therapy and specialist equipment. The model presented in this report could be easily transferred to assess the effectiveness of these other services. We are happy to make any part of our research available for further analysis of services.



Photograph supplied by Shared Care Network.

Appendices

Appendix 1: Recent estimates of the number of disabled children

	Reference	Definition	Estimated number of disabled children
1	Family Resources Survey 2002/03, Department for Work and Pensions. ⁵⁸	Disability Discrimination Act definition: Long-standing limiting illness or disability affecting one or more basic activities including moving around, communication and understanding when in physical danger. For children under 16 and 16-18 in full time education and living at home in Britain.	700,000
2	Department for Work and Pensions Information Directorate: Work and Pensions Longitudinal Study. Analysis May 2006. ⁹	Children receiving Disability Living Allowance, including Care and Mobility component. For children 0-18 in Britain.	328,200 (Care component: Higher Rate 121,700; Middle Rate 173,390; Low Rate 23,760; Nil Rate 9,340)
3	Re-analysis of Families and Children Study 2002, DWP. ¹⁶	Parents reported that child had either: i) Long-standing illness or disability resulting in extra care needs or affected school attendance. (ii) SEN due to physical disabilities. (iii) Intellectual disability that had significant impact on schooling. For children under 17 in Britain.	1.2 million
4	General Household Survey 2002, Office for National Statistics. ⁵⁹	Longstanding illness which limits activity. For children age 0-15 in Britain. NPC calculation: (3,431,000 x 0.04 children age 0-4) + (8,157,000 x 0.08 children age 5-15) using data presented in survey (table 7.1).	772,920
5	General Household Survey 2001, Office for National Statistics. ⁶⁰	Longstanding illness which limits activity. For children age 0-15 in Britain. NPC calculation: (3,278,000 x 0.1 children age 0-4) + (8,028,000 x 0.09 children age 5-15) using data presented in survey (table 7.2).	789,800
6	General Household Survey 1995, Office for National Statistics. ⁶¹	Longstanding illness which limits activity. For children age 0-15 in Britain NPC calculation: (1,564,000 x 0.04 children age 0 -4 + 3,532,000) x (0.08 children age 5-15) using data presented in table 7.162. NB: Large discrepancy between 1995 and 2001/2002 may be due to change in weighting methodology used in GHS in 1998.	345,120
7	OPCS disability surveys 1989. ⁶³	'Any restriction or lack of ability to perform activities considered normal for a person of similar age, which has resulted from the impairment of a structure or function of the body or mind.' Age 0-15 in Britain.	320,000

Appendix 2: Sources for the costs of short break services

Note: The fifth column 'Confidence rating' is our subjective measure of a source's reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

	Reference	Description	Data	Confidence rating
8	Carlin, J. and Cramer, H (in press) <i>Creative responses to changing needs? Fourth National Survey of Short break services for disabled children in the UK.</i> Shared Care Network. ⁴⁸	Most comprehensive survey available of 'shared care' short break services, updated for 2006. Survey includes responses from 120 schemes (94 public, 26 voluntary sector). Costs for financial year 2005/2006.	£44 UK average allowance/wage payment for short break carers per overnight/24h period. Carers on average linked on to 1.3 children. Carers receive an average of 14 hours training. 51% of disabled children placed are aged between 5 and 11. 34% are aged between 12 and 16. Additional information Contract carers are paid an average of £14,091 per annum. Where carers were paid weekly, the fee was an average of £233. Contract carers on average are linked to 5 children. 72% of carers required between 11 and 20 hours training. 55% of children placed are aged between 5 and 11. 34% are aged between 12 and 16. 63% care for between 16 and 20 nights per month. 26% between 10 and 15 nights. Sitters paid average £6.94 per hour. Each sitter is on average linked to 1.4 children. 64% required sitters to earn between 11 and 20 hours preparatory training.	* * *
9	Tapsfield, R. and Collier, F. (2005) <i>The cost of foster care: investing in our children's future.</i> The Fostering Network and BAAF. ⁶⁴	An analysis of the costs of providing foster care using national data and data provided by seven foster care providers (four public and three independent). Includes allowances paid to foster carers, fees, training and management. Costs for financial year 2004/05.	It costs £13,416 per year to support one foster carer (costs including recruitment, management, ongoing support, equipment and training). Figure is based on one social worker supporting 10 foster care households. Overheads are divided as follows (costs given per carer): Supporting social workers £3,249 Manager £860 Support groups for foster carers £240 Support for foster carers sons and daughters £40 * Out of hours crisis support £182 Support events for foster families £150 Support workers £1,322 * Educational support for foster child £1,645 * Equipment in foster home £2,296 Independent legal support £40 Administration £1,228 Panel (to approve foster carers) £200 Training costs (for staff) £240 Recruitment £1,725 TOTAL £13,416 This unit cost is likely to be lower for short break carers as a social worker can support more than 10 carers. (* indicates those costs excluded for short break carers.) ⁶⁵⁻⁶⁷ It costs around £40 for a 3.5 hour training session for foster carers. This equates to an hourly cost of £11.43.	* * *
10	Robinson, C. (2003) <i>Short breaks in the South West of England for Disabled Children and Adults with Learning Disabilities.</i> South West Learning Disability Network. ⁶⁸	A survey of short breaks available in the South West for children with learning disabilities from 13 councils. Questionnaire-based, followed up with telephone interviews. Costs for financial year 2001/02.	Unit cost of shared care scheme short breaks is £61.17 per day. Additional information: Unit cost £176.10 per day for residential (averaged between 21 in-house residential, voluntary sector and private sector scheme). Unit cost £12.30 per hour for sitting service (9 schemes).	*

	Reference	Description	Data	Confidence rating
11	Heslop, P., Byford, S. and Weatherly, H. (2003) <i>Better Rewards: the cost and effectiveness of employing salaried support carers to reduce waiting lists for short-term care</i> . Shared Care Network, Norah Fry Research Centre and University of York. ⁶⁹	Survey-based assessment of short break services. Intends to determine whether paying 'enhanced' carers on contract is more effective than just providing a basic 'standard' allowance. Data based on detailed questionnaires from ten schemes. Information on salaries, length of care, administration and equipment collected from schemes. Capital and overheads estimated on the basis of published costs for similar services (PSSRU 2001). Costs for financial year 2000/01.	Unit cost £37-284 for short breaks, provided by a 'standard' carer. Unit cost £97-592 for short breaks, provided by an 'enhanced' carer. Unit cost £14.31 for social services/Barnardo's sitting service for three hours.	*
12	Curtis, L. and Netten, A. (2005) <i>Unit Costs of Health and Social Care, Survey of Short break PSSRU</i> . ⁵ Chapter 4 'Services for people with learning disabilities'.	Unit cost information compiled annually by the University of Kent. Data drawn from a variety of sources. Costs for financial year 2004/05.	Unit cost £33 per session (morning, afternoon or evening) for local authority day care for adults with learning disabilities. Inflated to 2005/2006 prices this is £34. Unit cost £77 per session (£18 per hour) for voluntary sector, activity-based respite care for people with learning disabilities. Inflated to 2005/2006 prices this is £78. Unit cost of community homes for children £2,194 per day. Inflated to 2005/2006 prices this is £2,236. Unit cost of foster care is £477 per week. Inflated to 2005/2006 prices this is £486. Unit cost of a visit to a GP with a full prescription £53.40. Inflated to 2005/2006 prices this is £54.41.	* * *
13	Shared Care Network poll of social worker caseloads from short break services, 4 December 2006. ⁶⁵	Straw poll of 16 service providers (Norfolk, Essex, Leeds, Northern Ireland, and data from 12 Barnardo's schemes).	Mode for caseload is 20.	* *
Individual examples				
14	Interview with Bradford Metropolitan Borough council, Shared Care Network and Barnardo's. ⁶⁵⁻⁶⁷	Interview to determine the individual elements of cost to be included in the calculation of unit costs of short breaks.	Include costs for supporting social workers, manager, support groups, out of hours crisis support, support events, equipment, independent legal support, administration, panel, training costs and recruitment.	* * *
15	The Children's Trust. ⁹⁰	Severely disabled children. Costs prepared as part of management accounting and updated annually. Costs for financial year 2006/07.	Unit cost £454 per day. Includes on-site doctors and full-time nursing care.	* * *
16	Bradford Metropolitan Borough Council. ⁶⁷	Interview to determine unit cost of services. Costs for financial year 2005/2006.	Unit cost of £90-95 per break, based on the total budget for the scheme divided by the number of sessions provided.	* *
17	Metcalfe, R. (unpublished) <i>An exploration of costing and budgetary processes within the Children's Disability and Health Service 2005</i> . ⁷¹	Analysis of costing of services for Doncaster Metropolitan Borough Council. Costs for severely disabled children. Costs for financial year 2006/07.	Unit cost of £166.37 to £370.78 per 24 hour period for residential care short breaks.	* *
18	Barnardo's. ⁶⁶	Unit cost data provided by policy department. Based on information from Barnardo's Welsh short break service.	Unit cost £3,000 per year. Based on each child provided with a week-end short break once a month. Costs include project manager, carer allowances, training and reviews, and equipment costs. Does not include administration and management or office overheads. Day care for three hours a week (or 150 hours per year) costs £2,700.	* *
19	NCH internal cost data, provided by Clare Gent, Service Development Manager, NCH. ⁶⁶	Based on 33 residential short break services in the UK, provided for around 1,000 severely disabled children. Costs for financial year 2005/2006.	Unit cost £400 per night for residential services. Annual cost per child, based on three nights per month plus a holiday break is £16,000 per year. Shared care services with trained professional foster carer is £140 per night.	* *

Appendix 3: Sources for the outcomes of short break services

Note: The fifth column 'Confidence rating' is our subjective measure of a source's reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

	Reference	Description	Data	Confidence rating
20	Bruns, E.J. and Burchard, J.D. (2000) <i>Impact of Respite Care services for Families with children experiencing emotional and behavioural problems, Children's Services. Social Policy, research and Practice</i> 3 (1): p. 36-61. ⁷³	Longitudinal study of the effects of respite care on families with children with emotional and behavioural disabilities. Based on a sample of 33 children receiving respite care and a control sample of 28 waiting to receive services. Study from Vermont, USA.	Respite care significantly reduces parent's stress levels (measured by personal strain subscale) ($p < 0.1$). Respite care also increased parents' optimism and reduced anticipated need for services in the future. Respite care reduces the need for families to use home residential care placements. 15% of families used out of home placement before receiving respite and only 6% during. In contrast the comparison group increased from 29% to 32%.	* * *
21	Cowen, P.S. and Reed, D.A. (2002) <i>Effects of Respite Care for Children with Developmental Disabilities: Evaluation of an Intervention for At Risk Families</i>, Public Health Nursing 19 (4): p. 272-283. ⁷⁴	A study of 148 families before and after receiving respite care in a county of a rural mid-Western US state. A survey of Parenting Stress Index, foster care placements and child mistreatment in families.	Respite care caused a significant decrease in overall stress score of parents ($p = 0.0016$). Before the respite care 73% of parents were over dangerous stress levels, after 62% were over stress levels (NPC calculation from their stated standard deviation and mean). Assuming a normal distribution. The study also notes that high quality respite care programmes may have an effect on foster care placements. Foster care placement rate for the state was 6.3 per 1,000, compared to 4.8 for the county.	* *
22	Chan, J.B. and Sigafoos, J. (2001) <i>Does respite care reduce parental stress in families with Developmentally disabled children?</i> Child and Youth Care Forum 30(5). ⁷⁵	Review of existing published studies of the effects of respite care Includes studies between 1989 and 2000 from the US, UK and Australia.	The studies show that respite care is associated with significant reductions in parental stress, at least in the short-term.	* *
23	Heslop, P., Byford, S. and Weatherly, H. (2003) <i>Better Rewards: the cost and effectiveness of employing salaried support carers to reduce waiting lists for short-term care</i>. Shared Care Network, Norah Fry Research Centre and the University of York. ⁶⁹	Survey based assessment of short break services. Intends to determine whether paying 'enhanced' carers on contract is more effective than just providing a basic 'standard' allowance Data based on detailed questionnaires from ten schemes and interviews with 73 families receiving short breaks and 33 waiting to receive short breaks.	The health of parents of children that have received breaks deteriorates in the six months after first receiving short break services. 46% report emotional/psychological deterioration and 37% report physical deterioration ($n = 59$), compared to 67% and 0% in waiting list group ($n = 21$). Short breaks have no significant effect on the health of siblings. This pattern could be explained by the selection of families for short break services.	*
24	Sherman, B.R. (1995) <i>Impact of home-based respite care on families of children with chronic illness</i>. Children's Health Care 24: p.33-45. ⁷⁶	Study of 26 families caring for a child with a chronic illness. Measures stress and coping before and after receiving respite.	Reduced stress and improved quality of life among mothers. Statistically significant reduction in physical illness ($p < 0.05$). Results also suggest an association between respite care and a decrease in the number of hospital admissions required by child $p < 0.07$.	* *
25	Rimmerman, A. (1989) <i>Provision of respite care for children with developmental disabilities: Changes in maternal stress and coping over time</i>. Mental Retardation, 27(2): p.88-102. ⁷⁷	Study of 32 mothers of children with intellectual disability over an 18 month period. Compared stress and coping among families that use respite care ($n = 32$) with those that did not ($n = 25$).	Reduction in stress among mothers that used respite care. In comparison, for those not receiving respite, study showed increased stress and reduced coping.	* *

	Reference	Description	Data	Confidence rating
26	McNally, S. Ben-Shlomo, Y. and Newman, S. (1999) The effects of respite care on informal carers' well-being: a systematic review. <i>Disability & Rehabilitation</i> 21(1): p. 1-14. ⁷⁸	Review of 29 studies looking at the effects of respite care on the carers of those who look after someone with a chronic disability or illness. Includes both adults and children.	Study found little evidence that respite care has a consistent or enduring beneficial effect on carers' well-being. The author notes that this may be due in part to the fact that the work conducted has been methodologically poor.	*
27	Hoare, P., Harris, M. Jackson, P. and Kerley, S. (1998) <i>A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care.</i> <i>Journal of Intellectual Disability Research</i> , 42(3): p. 218-227. ⁷⁹	Study of the psychological and social characteristics of 143 children with severe disability. Compared distress among carers that use and do not use respite care. Using general health questionnaire.	Carers that use respite care have significantly greater 'total' distress ($p < 0.001$). The greater the amounts of respite usage the more distress among carers. It is likely that although respite care is a valuable resource its use is indicative of underlying distress in carers.	*
28	Botuck, S. and Winsberg, B.G. (1991) <i>Effect of respite on mothers of school-aged and adult children with severe disabilities.</i> <i>Mental Retardation</i> 29: p. 43-47. ⁸⁰	Study looking at the effect of respite care on 14 mothers with severe disabilities. Looked at changes in mothers' mood, well-being and activity.	Mothers had greater well-being and were less depressed during respite than they were before and after. Mothers also spent more time resting, sleeping, grooming and participating in leisure activities during respite.	*

Appendix 4: Sources for the costs of key worker services

Note: The fifth column ‘Confidence rating’ is our subjective measure of a source’s reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

	Reference	Description	Data	Confidence rating
29	Greco, V., Sloper, P., Webb, R. and Beecham, J. (2005) <i>An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs</i> . York University. ⁵³	A highly regarded nationwide study of key worker services. The costs of 14 were examined in depth. Costs for financial year 2005/2006.	Mean cost of £2,035 per family per year (NPC calculation from a sample of 12 established designated and non-designated services).	*
30	Young, A., Temple, B., Davies, L., Parkinson, G., Bolton, J., Milborrow, W., Hutcheson, G. and Davis, A. (2006) <i>Early Support: An Evaluation of Phase 3 of Early Support</i> . University of Manchester in association with the University of Central Lancashire. ⁶¹	A government funded evaluation of the Early Support program for children aged 0-3 years. The unit cost divides data on total project costs and number of beneficiaries from 45 Pathfinder projects across England. Costs for financial year 2005/2006.	£6,100 per family per year. The Early Support program calculation includes other elements of cost, such as the production of information materials. Approximately half of the families accessing these materials did not have a key worker, so the unit cost figure is significantly inflated.	*
31	Barton, L. (2006) <i>Altogether Now: An Evaluation of the Key Working Process in Warwickshire: Professional and Parental Views</i> . Warwickshire Council. ⁶²	Evaluation of the pilot key worker scheme in Warwickshire, involving designated and non-designated key workers. 86 families received support, and the report estimates that this could be scaled up to 144 families with little extra cost. Costs for financial year 2005/2006.	£3,034 per family per year for the pilot scheme. £1,812 per family per year (estimated) if the service were operated at full capacity.	* *

Appendix 5: Sources for the outcomes of key worker services

Note: The fifth column 'Confidence rating' is our subjective measure of a source's reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

Reference	Description	Data	Confidence rating
National studies			
32 Greco, V., Sloper, P., Webb, R. and Beecham, J. (2005) <i>An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs</i> . York University. ⁵³	The most comprehensive nationwide study of key worker services.	Outcomes: <ul style="list-style-type: none"> • Overall quality of life for families improved using QoL measure; • Better relationships with services; • Better and quicker access to statutory and discretionary benefits; and • Reduced levels of stress. <p>'We did not find any effects of key worker service variables on parental employment. Given the barriers to employment for parents with disabled children, especially those caused by lack of appropriate child care, this is perhaps not surprising.'</p> <p>The average amount of time families had used the service was three years four months.</p>	* * *
33 Sloper, P (2005) <i>National Services Framework: Standard 8 Disabled Children and Young People and Those with Complex Health Needs</i> . ⁸³	Brief comments from a literature review, in a broader document, by one of the leading academics covering disabled children.	Studies of key workers consistently report: <ul style="list-style-type: none"> • positive effects on relationships with services; • fewer unmet needs; and • greater family well-being. 	* *
34 Liabo, K., Newman, T., Stephens, J. & Lowe, K (2001) <i>A Review of Key Worker Systems for Disabled Children and the Development of Information Guides for Parents, Children and Professionals</i> . Wales Office of R&D for Health and Social Care. ⁸⁴	A literature review focused on key working.	Reviewed existing research and concluded that comparisons between families with and without key workers indicated that families having key workers have: <ul style="list-style-type: none"> • better relationships with services; • higher morale; less isolation and feelings of burden; • improvements in receipt of information and access to services; and • fewer unmet needs and more partnership with services. 	* * *
35 Young, A., Temple, B., Davies, L., Parkinson, G., Bolton, J., Milborrow, W., Hutcheson, G. and Davis, A. (2006) <i>Early Support: An Evaluation of Phase 3 of Early Support</i> . University of Manchester in association with the University of Central Lancashire. ⁸¹	A government initiated evaluation of 39 Pathfinder projects (for children aged 0-3 yrs), across England.	Views of some health professionals: <ul style="list-style-type: none"> • 'The greatest savings, in my opinion, come from reducing the emotional cost to families by giving them better support. There will also be some financial savings to families [such as] appointments.' • 'The coordinated approach and key worker service reduces the likelihood of family crisis and we may expect some cost savings.' • 'Well informed parents and families could have the effect of increasing the cost of service provision as they demand more.' <p>Other benefits listed by professionals include:</p> <ul style="list-style-type: none"> • reducing non-attendance at scheduled health appointments; • reducing family waiting times for follow-on referrals and services; and • avoiding bottlenecks in service access and delivery points. <p>Parents said benefits included:</p> <ul style="list-style-type: none"> • facilitating, enabling and chasing up appointments; • collecting evidence required for meetings; and • easing the organisational burden, thus enabling them to have more quality time with the whole family. 	* *

	Reference	Description	Data	Confidence rating
Local studies				
36	Horrocks, S., Salisbury, C, and Somerset, M. (2000) <i>An Evaluation of the Lifetime Service in Avon.</i> University of Bristol. ⁸⁵	An evaluation of a key worker service in Avon, with 16 families interviewed.	<p>Parents' health:</p> <ul style="list-style-type: none"> • A dramatic 68% improvement in their score for 'mental role limitation' a measure of emotional problems which inhibit functioning. • This result came from the SF-36 questionnaire (a standardised health evaluation tool) which was filled in by parents both before they received the assistance of a key worker, and then 7-12 months later. This is the area of health in which the parents of children with life limiting conditions differ by far the most with the general population, scoring only just over a third (31 compared to 84 in the general population), which had increased to 52 after 7-12 months with their key worker. <p>Parents' views:</p> <ul style="list-style-type: none"> • 84% satisfied or very satisfied with key worker. • 63% say their key worker has had a positive impact on their peace of mind, 49% on emotional/mental health, 45% on financial circumstances, 43% on feeling of control over life, 32% on physical health, 26% on time for self and 24% on relationships. • On average 3% felt that the key worker had had a negative effect in each area (possibly because of a bad personal relationship?). 	* *
37	East Sussex Local Authority (2006) <i>An Evaluation of the Early Support Programme and Care Co-ordination Scheme: Parental and Professional Views.</i> ⁸⁶	An evaluation of a key worker service in East Sussex, with 28 families interviewed.	<p>Quotes from Parents:</p> <ul style="list-style-type: none"> • 'Someone to phone around and chase people while we can get on and look after our child.' • 'My Key Worker is the most supportive understanding person I have had in the most difficult 16 months I have ever had.' • 'Without my Key Worker I don't think I would have come as far with my daughter as I have.' • 'As a family we value the extra support that this scheme has brought us very highly. We were thinking of moving away but with the high level of care our son is getting here has made us change our minds.' • 'We would have found it much harder to cope if we hadn't had our Key Worker there to support us. The scheme really provides a hugely necessary lifeline to families who are often desperate, bewildered and overwhelmed.' <p>97% were 'very satisfied' or 'satisfied' with key worker (61% 'very').</p>	* *
38	Hudson, L. (2005) <i>Care Coordination Service For 0 To 3's With Complex Care Needs. Luton.</i> ⁸⁷	An evaluation of a key worker service in Luton, with ten families interviewed.	<p>Benefits noted by parents:</p> <ul style="list-style-type: none"> • some improvement in time spent with siblings and partner; • help in identifying needed services; and • feeling of being treated as people not cases and their whole family needs were understood. 	* *

	Reference	Description	Data	Confidence rating
39	Salford Early Support (2006) <i>Parents and Carers Perspectives on Early Support Key Working in Salford.</i> ⁵⁶	An evaluation of a key worker service in Salford, with 11 families interviewed.	<p>Benefits noted by parents included:</p> <ul style="list-style-type: none"> • improved inter-professional communication, which cut down on the conflicting advice that they were receiving; • extra time for families; • information about services that they were unaware of; • increased confidence in speaking to doctors; and • 73% rated the positive impact on the family as 7/10 or better. <p>The impact of key working on care delivery appears to be greatest earlier in the child's life. All the parents reported a progressive tailing off in the amount of time they needed from their Key Worker. Parents allocated a key worker after their child's 2nd birthday; the impact was not so great because by that age they had already secured access to most services needed.</p> <p>Quotes:</p> <ul style="list-style-type: none"> • 'It has made our lives more normal.' • 'I don't miss stuff now – [the Key Worker] is there as a safety net.' • 'If I didn't have her, forms would not get filled in or sent off and my child would not have a place at school.' 	*
40	Pam Quilter, 'Team around the Child' Coordinator for South West Surrey (personal correspondence). ⁸⁸	Information related to the key worker service in South West Surrey.	<p>Outcomes include:</p> <ul style="list-style-type: none"> • Reduction in clinical / assessment visits. • Professionals attending coordination meetings can prioritise when to begin seeing/treating the child. <p>Examples:</p> <ul style="list-style-type: none"> • Two children with Downs Syndrome no longer need their annual hospital visit because they are seen at the coordination meeting. • For one family service providers agreed to contact the key worker for information about the child's condition, rather than the family. This resulted in improved delivery of services and increased privacy. • For children receiving palliative care, all health/service meetings are rolled into one coordination meeting every two months. 	*
41	Barton, L. (2006) <i>Altogether Now: An Evaluation of the Key Working Process in Warwickshire: Professional and Parental Views.</i> Warwickshire Council. ⁸²	An evaluation of the key worker service in Warwickshire, with 19 families interviewed.	<p>Benefits noted by parents included:</p> <ul style="list-style-type: none"> • reduced stress; • reduced stress; reduced the number of times they had to explain family needs; • reduced stress; increased co-ordination of service delivery; • reduced stress; secured additional support, services and resources; and • reduced stress; raised awareness of entitlements and empowered family voices. 	*
US studies – there do not seem to be key worker services as such in the US, but the 'Medical Home' model is a related form of care-coordination used by some primary health care providers.				
42	Palfrey, J.S., Sofis, L.A., Davidson, E.J., Liu, J., Freeman, L., and Ganz, M.L. (2004) <i>The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model. Pediatrics, 113(5): p. 1507-1516.</i> ⁸⁹	An evaluation of a care coordination service involving 6 health practices in Boston, covering 150 families.	<p>Families saying that coordination made it easier to:</p> <ul style="list-style-type: none"> • get early medical care when the child is sick (61.4%); • get early medical care when the child is sick (61.4%); get appointments (60.9%); • communicate with the child's doctor (60.9%); • get referrals to specialists (60.5%); • get resources for the child (59.7%); • understand the child's medical condition (56.3%); and • get prescriptions filled (56.0%). <p>There were statistically significant differences in parents' missed workdays and in children's hospitalisations.</p> <ul style="list-style-type: none"> • Parents missing >20 days of work per year fell from 26% to 14%; • hospitalisations reduced from 58% per year to 43%; • no change in emergency department visits or missed days of school. 	* *

	Reference	Description	Data	Confidence rating
43	Farmer, J.E., Clark, M.J., Sherman, A., Marien, W.E., Selva, T.J. (2005) <i>Comprehensive Primary Care for Children With Special Health Care Needs in Rural Areas</i> . Pediatrics 116: p. 649-656. ⁹⁰	An evaluation of a care coordination service in the Midwest, covering 51 families.	Significant decrease in the frequency of visits to care providers: <ul style="list-style-type: none"> • Children with >8 primary care visits a year fell from 32% to 12%. • Children with >6 specialty care visits a year fell from 56% to 35%. • The amount of hospitalizations and in-home care was unchanged. 	* *
44	Witt, W., Kasper, J.D. and Riley, A.W. (2003) <i>Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination</i> . Health Service Research 38: p. 1441–1466. ⁹¹	Analysis of data drawn from the 1994/1995 US National Health Interview Survey Disability Supplement.	Children with poor psychosocial adjustment were more likely to receive mental health services if their care was professionally coordinated.	* *
45	Strickland, B., McPherson, M., Weissman, G., van Dyck, P., Huang, Z.J. and Newacheck, P. (2004) <i>Access to the Medical Home: Results of the National Survey of Children With Special Health Care Needs</i> . Pediatrics 113 (5): p. 1485-1492. ⁹²	Analysis of a US-wide survey of disabled children.	Families receiving care coordination in the medical home model report: <ul style="list-style-type: none"> • Lower unmet care needs (10% to 23%). • Lower unmet family support service needs (2% to 8%). • Lower levels of delayed/forgone care (6% to 14%). 	* * *
46	Emerson, E. and Hatton, C. (2005) <i>The Socio-Economic Circumstances of Families Supporting a Child at Risk of Disability in Britain in 2002</i> . Lancaster University. ¹⁶	Survey of a sample of 7,070 families that contained at least one dependent child under the age of 17 from the Department for Work and Pensions' Family and Children Study.	32% of disabled children lived in a lone parent family, compared to 22% of other children. 32% of disabled children lives in a household where no parent was working for more than 16 hours per week, compared to 16% for other families. This pattern held true for both two parent families (15% and 5%) and lone parent families (66% and 50%).	* * *
47	Pinney, A. (2005) <i>Disabled children in residential placements</i> . ¹⁰	A report on disabled children in residential care in response to the recommendations made in the 2003 DfES report Disabled Children in Residential Placements. Uses a variety of data sources, including 2003 CiN data and PLASC.	There are 13,300 disabled children in England who are in long-term residential placements (excluding foster care): <ul style="list-style-type: none"> • 9,500 board at residential schools; • 2,100 are in residential care homes; and • 2,700 have spent more than six months in NHS wards. Using a figure of 700,000 for the total number of disabled children, this equates to 2% (0.019%). A separate analysis of the 2005 Children in Need survey reports that there are 6,000 looked after disabled children (see source 74 below). Looked after disabled children include those in foster care and those in residential care homes. Therefore, there are 3,900 disabled children in foster care. Pinney's analysis of the 2003 Children in Need survey also shows that there are 68% (1,435 out of 2,110) looked after disabled children in residential placements who have 'disability' as their primary need code. 18% have 'abuse or neglect' and 5% have 'family dysfunction' as their primary need code.	* * *

Appendix 6: Sources for financial benefit calculations

Note: The fifth column 'Confidence rating' is our subjective measure of a source's reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

	Reference	Description	Data	Confidence rating
48	Gordon, D., Parker, R., Loughran, F. and Heslop, P. (2000) <i>Disabled children in Britain: a reanalysis of the OPCS disability survey</i> . The Stationery Office. ²⁸	A collection of statistics, based on a reanalysis of the 1984 OPCS disability survey.	3% of mothers with a disabled child are in full-time employment (compared to 22% of all mothers), 13% working part time (compared to 39%) and 84% unemployed (compared to 39%).	* *
49	Russell, P. (2003) <i>Bridging the Gap: the childcare needs of families with a disabled child</i> . Survey for the Sure Start Unit, available from the Council for Disabled Children. ⁹³	Survey of the needs of families with a disabled child, based on a national survey of more than 2,000 families.	85% of mothers of disabled children would like to work, either full-time or part-time.	* *
50	Office for National Statistics (2006) Annual Survey of Hours and Earnings (ASHE). ⁹⁴ http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=14630	Annual survey of the salary and hours of employees in the UK.	The median hourly wage for a part-time female employee is £7. The mean is £9.05.	* * *
51	Office for National Statistics (2004) Annual statistics on population and family structure. ⁹⁵ http://www.statistics.gov.uk/CCI/nugget.asp?ID=1163	Annual statistics on population and family structure.	There are 1.8 children per family.	* * *
52	Ofsted (2003) <i>Pupils with emotional, behavioural and social difficulties in mainstream schools. Special educational needs in the mainstream</i> . Annex 2, p.7. ⁹⁶ http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.summary&id=3408	Survey of schools provision for EBSD. With visits. Survey of 13 primary schools, two middle and 18 secondary schools in a representative sample of LEAs and schools.	Additional costs of EBSD varies considerably and difficult to identify. Average costs per child in primary school were about £1,000. In secondary and middle schools they were about £3,000. Inflated to 2005/2006 prices, this becomes £1,078 and £3,235 respectively.	* *
53	Monica McCaffrey, Chief Executive of Sibs, personal communication. ⁴⁶	Survey of head teacher in school with 22 siblings of disabled children.	73% of siblings of children with disabilities have academic problems.	*
54	Sahler, O., K. Roghmann, P. Carpenter, R. Mulhern, M. Dolgin, J. Sargent, O. Barbarin, D. Copeland and L. Zeltzer (1994) <i>Adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptational levels. Developmental and Behavioral Pediatrics 15: p. 353-366.</i> ⁴³	Study looking at the behaviour problems in siblings of children with cancer. Survey of parents of 254 siblings aged 4-18 of children with cancer in the US.	Prevalence rate of behaviour problems, 18% (7.7% of siblings had problems prior to diagnosis, 10.3% developed problems after diagnosis). Young children were found to be more vulnerable than older ones.	* *

	Reference	Description	Data	Confidence rating
55	Tew, B. and Laurence, K. (1973) <i>Mothers, brothers and sisters of patients with spina bifida.</i> Developmental Medicine and Child Neurology 15 (suppl.29): p. 69-76. ⁴²	Survey of teachers to look at the adjustment of siblings of children with spina bifida. Based on a sample of 44 siblings and 63 normal controls in the UK ages 2-15.	Siblings of children with spina bifida were nearly four times more likely to score above clinical cut-off points in behaviour problems compared to controls.	*
56	Sharpe, D. and Rossiter, L. (2002) <i>Siblings of children with a chronic illness: A meta-analysis.</i> Journal of Pediatric Psychology 27: p. 699-710. ⁴⁴	A review of 51 published sources pertaining to the siblings of children with a chronic illness.	There is a modest negative effect for siblings of a disabled child relative to comparisons.	** *
57	Fisman, S., Wolf, L., Ellison, D. and Freeman, T. (2000) <i>A longitudinal study of siblings with chronic disabilities.</i> The Canadian Journal of Psychiatry 45: p. 369-375. ⁹⁷	An examination of the unaffected siblings of groups with pervasive developmental disorder and down syndrome.	Significantly more adjustment problems are found in the siblings of pervasive developmental disorder.	** *
58	Breslau, N., Weitzman, M. and and Messenger, K. (1981) <i>Psychologic functioning of siblings of disabled children.</i> Pediatrics 67: p. 344-353. ⁹⁸	A study of 239 families with children with cystic fibrosis, cerebral palsy, myelodysplasia and multiple handicaps and normal siblings in Cleveland compared with data on 1,034 randomly selected children from a cross-section of Manhattan Households.	Siblings scored significantly higher than the comparison sample on mentation problems, fighting and delinquency.	** *
59	Williams, P. (1997) <i>Siblings and pediatric chronic illness: a review of the literature.</i> International Journal of Nursing Studies 34, 312-323. ⁹⁹	A review of 40 published studies to identify the extent and nature of risks to siblings of chronically ill children.	60% of studies reported an increase in sibling risk, 30% reported no risk and 10% had positive and negative outcomes.	** * *
60	Department for Education and Skills (2006) <i>Statistical First Release: Special Educational Needs in England, January 2006.</i> ¹⁰⁰ http://www.dfes.gov.uk/rsgateway/DB/SFR/s000661/SFR23-2006v2.pdf	Statistical bulletin based on the Schools' Census and SEN2 survey. Data from Table 9 'Maintained primary, secondary and special schools: Number and percentage of pupils by type of need' (England only).	16.8% of pupils have SEN. 20% of pupils with SEN have EBSD. Rate of EBSD is therefore 4%.	** *
61	Dockrell, J.E., Peacey, N., and Lunt, I. (2002) Literature Review: Meeting the Needs of Children with Special Educational Needs, Institute of Education, University of London. ¹⁰¹	Literature review of needs and types of special educational needs.	Estimates the overall rate of EDB to be 3-7%.	*

	Reference	Description	Data	Confidence rating
62	Cadman, D., Boyle, M., and Offord, D. <i>The Ontario Child Health Study: social adjustment and mental health of siblings of children with chronic health problems.</i> Behavioral Pediatrics 9: p. 117-121. ⁴⁵	Survey of mother, child with illness, sibling and teacher to look at associated health problems and mental health of siblings of children with chronic illness. Sample includes 3,294 children in Ontario ages 4-16.	Siblings of children with a chronic illness had a two-fold increase in risk of emotional disorders.	* *
63	Department for Education and Skills (2005) <i>National Curriculum Assessment, GCSE and Equivalent Attainment and Post-16 Attainment by Pupil Characteristics, in England 2005.</i> http://www.dfes.gov.uk/rsgateway/DB/SFR/s000640/Addition1.xls	Annual statistics bulletin on the attainment of all schoolchildren in England.	63.3% of children with no SEN gain five A*-C grades, 98.5% gain any pass. 17% of children with SEN without a statement gain five A*-C grades, 91.5% gain any pass. 7.1% of children with a statement of SEN gain five A*-C grades, 8.6% gain any pass.	* * *
64	Godfrey, C., Hutton, S., Bradshaw, J., Coles, B., Craig, G. and Johnson, J. (2002) <i>Estimating the cost of being 'not in education, employment or training' at age 16-18.</i> DFES Research Report RR346. ¹⁰³	Study looking at the short, medium and long-term costs of being not in education, employment or training (NEET) at 16-18. Includes the cost of unemployment and underemployment. Covers England & Wales.	Medium-term costs of educational underemployment per week. Foregone earnings: £193.3 for men, £117.6 for women. Lost contributions: £42.91 for men, £26.11 for women. Lost direct tax: £21.26 for men, £12.49 for women. Lost indirect tax: £36.65 for men, £22.30 for women. One extra GP consultation with a prescription is £33.67. Average number of GP visits is three for men and five for women. Medium-term cost of unemployment. Lost earnings: £343.90 for men, £337.60 for women. JSA and HB: £129.95 for men, £110.95 for women. Lost contributions: £59.52 for men, 58.12 for women. Lost direct tax: £37.83 for men, £37.14 for women. Lost indirect tax: £66.81 for men, £65.62 for women.	* * *
65	Catalano, R. and Dooley, D. (1983) <i>The Health Effects of Economic Instability: A Test of Economic Stress Hypothesis.</i> Journal of Health and Social Behavior 24: p. 46-60. ¹⁰⁴	Longitudinal survey data to determine links between short-term community economic change and illness or injury. Sample of 6,190 subjects in LA.	Experiencing an undesirable job or financial event nearly doubles the odds of illness or injury.	*
66	Mind (2005) <i>Stress and Mental Health in the Workplace.</i> ¹⁰⁵	Survey of employees and employers in the UK on issues surrounding stress.	45 million working days are lost to general stress and anxiety. 20% of workers suffer from stress levels described as 'very' or 'extremely' stressful.	* *
67	Carmichael, F. and Charles, S. (1998) <i>The labour market costs of community care.</i> Journal of Health Economics 17: p. 747-765. ¹⁰⁶	An investigation into the impact of caring on the labour supply of women based on responses to the 1985 National Household Survey.	Carers who care for more than 30 hours per week who work, work on average 25.7 hours per week at a weekly wage of £262. 10% reduction in earnings capacity of those caring 20 hours or more per week. A mother-carer is expected to work 18 hours per week if in the labour market.	* * *
68	Singleton, N., Maung, N., Cowie, A., Sparks, J., Bumpstead, R. and Meltzer, H. (2002) <i>Mental Health of Carers.</i> The Stationary Office. ³⁶	A follow-up of adults interviewed in the 2000 General Household Survey. Carers identified in the 2000 GHS.	32% of carers have CIS-R score of over 12 (considerable neurosis) and 23% are over 18 which is the level at which treatment is required. 29% of carers with CIS-R scores of over 12 were receiving at least one form of treatment: 17% receiving medication, 7% receiving medication and counselling, 5% receiving counselling only.	* * *

	Reference	Description	Data	Confidence rating
69	Office for National Statistics (December 2006). <i>Labour Market Trends</i> . ¹⁰⁷	Survey of the UK labour market.	Size of the workforce is 29 million. NPC's own calculation: if 20% of these are stressed and 45 million sick days are taken per year due to stress than the number of sick days per stressed person = 45 million ÷ (0.2 x 29million) = 8.	* * *
70	Office for National Statistics (2000/2001) <i>Household Survey</i> . ¹⁰⁸ http://www.statistics.gov.uk/StatBase/Expodata/Spreadsheets/D6512.xls	The GHS is conducted on a sample of approximately 13,000 addresses in the UK each year.	The average number of visits to a GP per year is four.	* * *
71	SEN Regional Partnerships (2004) <i>Analysis of Out-Of-Authority Placements</i> . ¹⁰⁹	A survey of the cost and types of out-of-authority placements made by local authorities in the UK.	There is a 20-fold variation in the number of out-of-authority placements made by local authorities – ranging from about ten placements per 100,000 children to nearly 200.	* * *
72	Department for Education and Skills (2003) <i>An Investigation into the funding of SEN provision in schools and education and elsewhere</i> . ¹⁵	An investigation into SEN expenditure in the UK.	'Many placements are made because of a lack of suitable alternative local provision or because of difficulties in social care.'	* *
73	Morris, J., Abbott, D. and Ward, L. (2002) <i>At Home or Away? An Exploration of Policy and Practice in the Placement of Disabled Children at Residential Schools</i> . <i>Children & Society</i> 16, 3-16. ¹³	A paper looking at the patterns of residential placements and the reasons for them in 21 education and social service authorities in England.	'In the opinion of both education and social services officers, the commonest reason for a residential placement was the effect of a child's impairment on the family'.	* *
74	Personal communication with Isabella Craig, Statistician at the Department for Education and Skills, 25 January 2007. ¹²	DfES internal analysis of the 2005 Children in Need Survey.	There are 6,000 looked after disabled children (after excluding those who were on short breaks or respite care on the survey day). We know from Pinney's analysis (see source 47) that 2,100 of these are in residential homes, therefore there are 3,900 disabled children in foster care.	* * *
75	The Office for National Statistics (2006) <i>GDP Deflator</i> . ¹¹⁰ http://www.hm-treasury.gov.uk/media/5D3/0E/gdpdeflators_061206.xls	The GDP deflators are constructed from ONS single GDP series for current and constant prices.	The ratio used to inflate 2004/2005 prices to 2005/2006 prices is 1.0190 and from 2002/2003 prices to 2005/2006 prices is 1.0782.	* * *

Appendix 7: Sources of family breakdown

Note: The fifth column 'Confidence rating' is our subjective measure of a source's reliability. In making this judgement, we consider how relevant the source is and the quality of the data (eg, sample size, control group, geographical location etc.).

	Reference	Description	Data	Confidence rating
76	Sobesity, D. (2004) <i>Marital stability and marital satisfaction in families of children with disabilities: chicken or egg?</i> Developmental Disabilities Bulletin, 32(1), pp. 62-83. ²⁶	Literature review of studies on marital satisfaction and stability published since the 1970s. Points out a bias in society towards looking for disability as the cause of marital breakdown. Concludes that the evidence is mixed. Most studies seem to suggest that there is no significant relationship. If there is a positive relationship then it is small.	Evidence mixed. Small or non-existent relationship between child disability and separation, likely to be in the range 1-5%.	* * *
77	Mauldon, J. (1992) <i>Children's risks of experiencing divorce and remarriage: do disabled children destabilize marriages,</i> Population Studies, 46(2), pp. 349-362. ²³	Study of divorce and remarriage in the US using a sample of over 10,000 children. Splits sample into three set divorce at ages 0-2, 2-5 and 6-9.	Difference between disabled and non-disabled children parents' divorce rates is significant only in ages 6-9 ($p < 0.05$). 'A 'disabled' child between six and nine years would face a 9.5% risk of divorce, compared to a 4.9% risk for an otherwise identical non-disabled child.' Criticisms: narrow age band for significant results, not a very robust test of significance given the large sample size.	* * *
78	Sabbeth, B.E. and Leventhal, J.M. (1984) <i>Marital adjustment to chronic childhood illness: a critique of the literature.</i> Pediatrics 72, 762-768. ²⁷	Literature review of effect of childhood illness on marriage. Based on 23 studies, seven with comparison groups. No studies of divorce.	Concludes that the evidence is mixed. Four studies showed evidence of marital discord; three found no significant differences.	* *
79	Reichman, N.E., Corman, H. and Noonan, K. (2004) The effect of child health on parents' relationship status. Demography, 41(3), 569-584. ²²	Data from Fragile Families and Child Wellbeing Study. Looked at whether fathers lived in the same household 12-18 months after birth.	Over the period, having a child with poor health decreased the probability that the parents lived together by ten percentage points.	*
80	Corman, H. and Kaestner (1992) <i>The effects of child health on marital status and family structure.</i> Demography, 29(3), 389-408. ²¹	Based on a sample of 9,000 families from the 1988 US National Health Interview Survey's Child Health Supplement. This is US data and shows significant differences.	For mothers married at the time of birth the presence of a child who is either developmentally delayed or physically disabled is associated with a significant reduction in the likelihood of being married by four percentage points.	* *
81	Eddy, L.L. And Walker, A.J. (1999) <i>The impact of children with chronic health problems on marriage.</i> Journal of Family Nursing, 5(1), 10-32. ²⁴	Using data from the US National Study of families and Households. Contrasts 94 married couples with a child with a chronic illness with 3,692 with a well child.	Neither marital quality nor perceived marital stability differed between the two groups.	* *
82	Fertig, A.R. (2004) <i>Healthy baby, healthy marriage? The effect of children's health on divorce.</i> Indiana University. ²⁰	Data from the US 1988 National Health Interview Survey, the national Longitudinal Survey of Adolescent Health and the 1970 British Birth Cohort.	In the UK, low birth weight children are no more likely to experience divorce than children of normal birth weight. In the US, they are more likely to experience divorce.	* *

	Reference	Description	Data	Confidence rating
83	Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y., and Hong, J. (2001) <i>Life course impacts of parenting a child with a disability</i> . American Journal on Mental Retardation, 106(3), 265-286. ²⁵	A longitudinal study of a cohort of 7,000 Wisconsin High School graduated from age 18 to 54.	Parents who had children with developmental disabilities differed from parents who had other children on variables such as income but did not differ from other parents in physical health, psychological well-being or marital status.	* *
84	Haskey, J. (1996) Population Trends: Divorce and Children. Population Trends 84. ¹¹¹	Average age of children at divorce.	7 years.	* *
85	Rent Right website. http://www.rentright.co.uk/00_00_00_1_00_rrpi.aspx ¹¹²	Average rent on a one-bedroom flat in the UK. The Residential Rental Price Index uses data from the Rent Right Website to provide average prices for rental property throughout the UK.	£710 per month, January 2007. £8,520 per year.	* *
86	Norwich Union 'Cost of Divorce' survey 2006. http://www.aviva.com/index.asp?PageID=44&year=&newsid=2935&filter=UKLIFE ¹¹³	Survey looking at how much couples spend when they part. Survey based on sample of 400 people in the UK in October 2006.	Legal fees £1,818 (51% of people). Average cost = £927 Cost of setting up a new home £5,146 (41% of people). Average cost = £2,110. Total cost = £3,037.	* *
87	Office for National Statistics (2007) News release: Housing-related costs average £140 a week. Family spending 2006 – results of the Expenditure and Food Survey 2005/06. ¹¹⁴	Survey of cost of running a household.	Across all households, average weekly spending included: £49 mortgages. £25 housing alterations/improvements. £23 on council tax, water charges and other local taxes and service charges. £16 on rent net of rebates and benefits.	* * *

Appendix 8: Supplementary note

Targeting resources at children at risk of going into residential placements

This supplementary note investigates the implications for the financial benefits of services from targeting at children at risk of going into residential placements (including residential schools and care homes).

The sources used in the discussion below are referenced in the same way as in the main report, *What price an ordinary life?*.

Why target services?

We know from anecdotal evidence that living with a disabled child affects all families differently.¹ Therefore, it is likely that some children and families will benefit more than others from access to short break and key worker services. If we are trying to achieve the maximum benefit for society, then some targeting of resources would be efficient.

In the main report we looked at the average financial benefits of short break and key worker services to a spread across a population of all disabled children (700,000 children).⁷ In this note we attempt to estimate the financial benefits if these services were targeted at children at risk of going into residential placements.

Defining children at risk of going into residential placements

There is no straightforward way of defining children at risk of going into residential placements. However, we know that these children are more likely to be severely disabled than those not in residential placements. If we can estimate the total number of severely disabled children then we can use this as a proxy.

One way of estimating the number of severely disabled children is to use the number of children who receive the higher rate of Disability Living Allowance (DLA). The DLA is a welfare benefit awarded to children on the basis of their care needs.^{115, 116} The number of children in the UK receiving the higher rate care component of the DLA is 121,700, or 17% of all disabled children.⁹ We assume that these children are most at risk of going into residential placements.

Characteristics of children in residential placements

There are 11,600 disabled children in residential placements: 2,100 in children's homes; 6,100 boarding in state-maintained schools; and 3,400 boarding in independent schools.^{10, 12}

Data from the 2003 Children in Need survey shows that 1,435 out of 2,110 looked after disabled children in residential placements, or 68%, have 'disability' as their primary need code.¹⁰ We assume that these children, who are looked after primarily because they are disabled rather than for social reasons (eg, abuse or neglect, family dysfunction or parent illness/disability), correspond exactly to those children who are eligible for higher rate DLA and that this pattern of disability is replicated across all 11,600 children. This means that there are 5,618 children in residential placements eligible for higher rate DLA. This is equivalent to 6% of all children claiming higher rate DLA. Under these assumptions children claiming the higher rate of DLA have a higher risk of going into residential placements.

Preventable costs

Not all children can be looked after at home; some need residential education or care. As in the main report, *What price an ordinary life?*, we assume that those children with multiple disabilities cannot be looked after at home. Data from the 2003 Children in Need survey shows that 1,110 out of 2,110 children, or 53% of children in residential placements, have multiple disabilities [47]. We assume that this pattern of disability is replicated across all residential placements (both social and educational). Therefore 3% (47% x 6%) of children eligible for higher rate DLA can be prevented from going into residential care.

Below we calculate the total preventable cost of children at risk of residential placements.

Calculations

- 1 Based on the Department of Work and Pensions DLA data and the 2003 Children in Need survey results presented above, 6% of all children claiming higher rate DLA are in residential care.
- 2 We assume that 47% of residential placements are preventable [47].
- 3 The costs of residential care vary substantially, depending on the provider and the needs of the child, e.g. [17]. We use a unit cost per week of £2,236, taken from the Personal Social Services Research Unit’s Unit Costs of Health and Social Care [12].

Paragraph:	1	2	3							
Cost of Residential Care	=	Percentage of disabled children eligible for higher rate DLA in residential care	x	Percentage of residential placements considered to be preventable	x	Cost per place per week	x	Weeks in a year	=	£3,572 per year per child
	=	6%	x	47%	x	£2,236	x	52	=	

Added to all the other preventable costs mentioned in the main paper, the total preventable cost for children at risk of residential placements is **£8,279** per child per year.

Over 15 years, based on a discount rate of 3%, the total cost is **£101,472**.

Comparing financial costs and financial benefits

Figure 4 compares the total preventable costs and the total financial benefits of (a) services for all disabled children and (b) targeting services at children at risk of residential placement. Costs are given for each service over 15 years using the same estimates of proportions of savings given in the main report *What price an ordinary life?*.

The height of each bar indicates the total preventable cost. The dark blue section of each bar indicates the financial benefit of each service. The blue lines indicate the cost of providing services.

The figure shows that the total preventable cost (the costs that potentially could be saved) are greater when targeting services than when providing services to all disabled children. Correspondingly, the total financial benefits are also greater. The costs of providing services remain the same.

Short break services

When targeting services at disabled children at risk of going into residential placement, the cost of providing short break services is less than the total preventable cost. The opposite is true when providing the service to all disabled children. However, the financial cost of providing short breaks still exceeds their financial benefit.

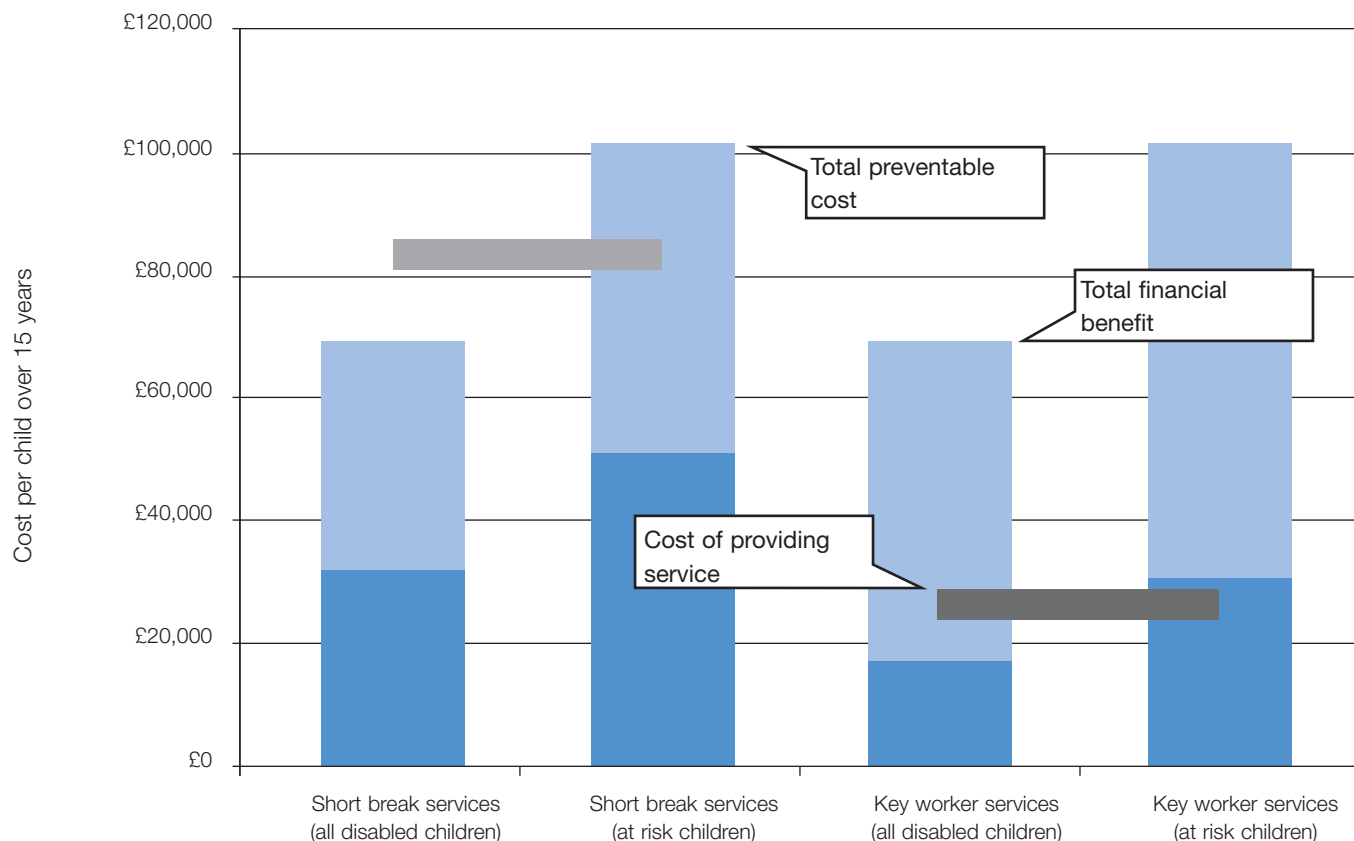
Short break services for at risk children save 50% of the total preventable cost. To match the cost of providing the services—or ‘break even’—they would need to save 80%, an increase of 30 percentage points.

Key worker services

When targeting services at disabled children at risk of going into residential placement, the cost of providing key worker services is less than the total financial benefit.

This implies that there is a straightforward economic case for investment.

Figure 4: A comparison of the costs and benefits of providing services to all disabled children and children at risk of residential placement over 15 years



Total preventable cost (all disabled children) = £68,781	
Total preventable cost (at risk children) = £101,472	
All disabled children:	
Total financial benefit of short break services = £30,737	Total financial benefit of key worker services = £16,981
Disabled children at risk of residential placement:	
■ Total financial benefit of short break services = £50,351 ■ Total cost of providing short break services = £81,584	■ Total financial benefit of key worker services = £30,057 ■ Total cost of providing key worker services = £25,023

Extending this analysis

This note demonstrates the financial benefits of targeting services at one group of children. The estimates given here are tentative, given the limitations of the data available on such a specific population. Similar analysis could be done on other groups of disabled children (eg, low income families, disabled children with EBD, or families with more than one disabled child) to work out the most effective way of using resources.

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References

- 1 New Philanthropy Capital (2005) *Ordinary lives. Disabled children and their families: a guide for donors and funders.*
- 2 Web of Knowledge (Online database of academic journals) website, <http://portal.isiknowledge.com/portal.cgi> [accessed on November - December 2006].
- 3 Bath Information and Data Services (BIDS) and IngentaConnect (online database of academic journals) website, <http://www.bids.ac.uk/> [accessed on November - December 2006].
- 4 Limbrick, P. *Interconnections Electronic Bulletin: About children and young people with disabilities/SEN.* Sent 5 November 2006 .
<http://www.icwhatsnew.com/bulletin/bulletin.htm>.
- 5 Curtis, L., and Netten, A., (2005) *Unit costs of health and social care.* Personal Social Services Research Unit.
- 6 HM Treasury website, http://www.hm-treasury.gov.uk/economic_data_and_tools/gdp_deflators/data_gdp_fig.cfm [accessed on 11 December 2006].
- 7 Department for Work and Pensions Information and Analysis Directorate (2004) *Press release: Estimate of the number of disabled children in Britain covered by the Disability Discrimination Act (1995).*
- 8 Personal communication with Higginbottom, N., *Disability and Carers Directorate, Department for Work and Pensions* (November 2004).
- 9 Department of Work and Pensions Information Directorate (2006) *Work and Pensions Longitudinal Study, bespoke information request. Analysis based on May 2006 data.*
- 10 Pinney, A. (2005) *Disabled children in residential placements.* Department for Education and Skills.
- 11 Kagan, C., Lewis, S., and Heaton, P. (1998) *Caring to Work: Parents Combining Employment with the Care of Disabled Children.* Family Policy Studies Centre, London.
- 12 Personal communication with Isabella Craig, Statistician, Children Young People and Families Directorate, Department for Education and Skills (25 January 2007).
- 13 Morris, J., Abbott, D., and Ward, L., (2002) *At home or away? An exploration of policy and practice in the placement of disabled children at residential schools.* Children and Society, 16: p. 3-16.
- 14 Sherman, B.R., and Coccozza, J.J., (1984) *Stress in Families of the Developmentally Disabled: a literature review of factors affecting the decision to seek out-of-home placements.* Family Relations, 33(1): p. 95-103.
- 15 Department for Education and Skills (2003) *An Investigation into the funding of SEN provision in schools and education and elsewhere.*
- 16 Emerson, E., and Hatton, C. (2005) *The socio-economic circumstance of families supporting a child at risk of disability in Britain in 2002.* Institute for Health Research, Lancaster University.
- 17 Department for Education and Skills and Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Standard 8 Disabled children and young people and those with complex needs.*
- 18 Contact a Family (2004) *No time for us: relationships between parents who have a disabled child. A survey of over 2,000 parents in the UK.*
- 19 Mencap (2003) *Breaking point: a report on caring with out a break for children and adults with severe or profound learning disabilities.*
- 20 Fertig, A.R. (2004) *Healthy baby, healthy marriage? The effect of children's health on divorce.* Indiana University.
- 21 Corman, H., and Kaestner, R., (1992) *The effects of health on marital status and family structure.* Demography, 29(3): p. 389-408.
- 22 Reichman, N.E., Corman, H. and Noonan, K., (2004) *The effect of child health on parents' relationship status.* Demography, 29(3): p. 569-584.
- 23 Mauldon, J. (1992) *Children's risks of experiencing divorce and remarriage: do disabled children destabilise marriage?* Population Studies, 46(2): p. 349-362.
- 24 Eddy, L.L., and Walker, A.J., (1999) *The impact of children with chronic health problems on marriage.* Journal of Family Nursing, 5(1): p. 10-32.
- 25 Seltzer, M.M., Greenberg, J.S., Floyd, F.J., Pettee, Y., and Hong, J., (2001) *Life course impacts of parenting a child with a disability.* American Journal on Mental Retardation, 106(3): p. 265-286.
- 26 Sobsey, D. (2004) *Marital stability and marital satisfaction in families of children with disabilities: chicken or egg?* Developmental Disabilities Bulletin, 32(1): p. 62-83.
- 27 Sabbeth, B.E., and Leventhal, J.M., (1984) *Marital adjustment to chronic childhood illness: a critique of the literature.* Pediatrics, 72: p. 762-768.
- 28 Gordon, D., Parker, R., Loughran, F. and Heslop, P., (2000) *Disabled children in Britain: A re-analysis of the OPCS disability survey.* The Stationery Office.
- 29 Curran, A.L., Sharples, P.M., White, C., and Knapp, M., (2001) *Time costs of caring for children with severe disabilities compared with caring for children without disabilities.* Developmental Medicine and Child Neurology, 43: p. 529-533.
- 30 Preston, G. (2005) *Helter Skelter: families, disabled children and the benefit system.* Centre for Analysis of Social Exclusion, CASEpaper 92.
- 31 Dobson, B., and Middleton, S., (1998) *Paying to care: the cost of childhood disability.* Joseph Rowntree Foundation.
- 32 Kempson, E. (2002) *Over-indebtedness in Britain.* Department for Trade and Industry.
- 33 Beresford, B., and Oldman, C. (2002) *Housing matters: national evidence relating to disabled children and their housing.* Joseph Rowntree Foundation.

- 34 Wallander, J.L., and Varni, J. W., (1998) *Effects of pediatric chronic physical disorders on child and family adjustment*. Journal of Child Psychology and Psychiatry, 39(1): p. 29-46.
- 35 Wilker, L. (1981) *Chronic stresses of families of mentally retarded children*. Family Relations, 30(2): p. 281-288.
- 36 Singleton, N., Aye Maung, N., Cowie, A., Sparks, J., Bumpstead, R., and Meltzer, H., (2002) *Mental Health of Carers*. Office for National Statistics.
- 37 Hirst, M. (2004) *Health inequalities and informal care: end of project report*. University of York, Social Policy Research Unit.
- 38 Carers UK (2004) *In poor health: the impact of caring on health*.
- 39 New Philanthropy Capital (2005) *Valuing short lives: Children with terminal conditions, a guide for donors and funders*.
- 40 Singleton, N., Bumpstead, R., O'Brien, M., Lee, A., and Meltzer, H., (2001) *Psychiatric morbidity among adults living in private households, 2000*. Office for National Statistics.
- 41 Layard, R. (2004) *Mental health: Britain's biggest social problem*. Strategy Unit Seminar paper.
- 42 Tew, B., and Laurence, K., (1973) *Mothers, brothers and sisters of patients with spina bifida*. Developmental Medicine and Child Neurology, 15(29): p. 69-76.
- 43 Sahler, O., Roghmann, K., Carpenter, P., Mulhern, R., Dolgin, M., Sargent, J., Barbarin, O., Copeland, D., and Zeltzer, L., (1994) *Adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptational levels*. Developmental and Behavioral Pediatrics, 15: p. 353-366.
- 44 Sharpe, D., and Rossiter, L., (2002) *Siblings of children with a chronic illness: a meta-analysis*. Journal of Pediatric Psychology, 27(2): p. 699-710.
- 45 Cadman, D., Boyle, M., and Offord, D., (1988) *The Ontario Child Health Study: social adjustment and mental health of siblings of children with chronic health problems*. Developmental and Behavioral Pediatrics, 9(117-121).
- 46 Personal communication with Monica McCaffrey, Chief Executive, Sibs (9 November 2006).
- 47 Tarleton, B., and Macaulay, F., (2002) *Better for the break? Short break services for children and Teenagers with Autistic spectrum disorders and their families*. Shared Care Network.
- 48 Carlin, J., and Cramer, H., (2006, in press) *Creative responses to changing needs: the fourth national survey of family-based short break services for disabled children*. Shared Care Network.
- 49 Shared Care Network (2006) *Still Waiting? Report on families of disabled children in the UK waiting for short break services*.
- 50 Beecham, J. (2000) *Unit costs - Not Exactly Child's Play: A guide to estimating unit costs for children's social care*. Department of Health, Personal Social Services Research Unit and Dartington Social Care Research Unit.
- 51 Audit Commission (2003) *Services for disabled children: a review of services for disabled children and their families*.
- 52 Care Coordination Network UK website, www.ccnuk.org.uk [accessed on 28 November 2006].
- 53 Greco, V., Sloper, P., Webb, R. and Beecham, J., (2005) *An Exploration of Different Models of Multi-Agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs*. Department for Education and Skills Research Report 656.
- 54 Beecham, J. (2001) *Disabled children and their families: the research evidence*. Personal Social Services Research Unit Discussion Paper 1708.
- 55 Social Care Institute for Excellence (2005) *SCIE Research briefing 5: Short breaks (respite care) for children with learning disabilities*.
- 56 Salford Early Support (2006) *Parents and Carers Perspectives on Early Support Key Working in Salford*.
- 57 The Sainsbury Centre for Mental Health (2003) *Policy Paper 3: The economic and social costs of mental illness*. The Sainsbury Centre for Mental Health.
- 58 Department for Work and Pensions (2003) *Family Resources survey 2002-03*.
- 59 Rickards, L., Fox, K., Roberts, C., Fletcher, L. and Goddard, E. (2004) *Living in Britain (No. 31). Results from the General Household Survey*. HMSO.
- 60 Walker, A., O'Brien, M., Traynor, J., Fox, K., Goaddard, E. and Foster, K. (2002) *Living in Britain. Results from the 2001 General Household Survey*. HMSO.
- 61 Rowlands, O., Singleton, N., Maher, J. and Higgins, V. (1997) *Living in Britain: Results from the 1995 General Household Survey*. HMSO.
- 62 Rowlands, O., Singleton, N., Maher, J. and V., H. (1997) *Living in Britain. Results from the 1995 General Household Survey*. The Stationary Office.
- 63 Bone, M., and Meltzer, H., (1989) *OPCS surveys of disability in Great Britain. Report 3: The prevalence of disability among children*. Office of Population Censuses and Surveys. Social Survey Division.
- 64 Tapsfield, R., and Collier, F., (2005) *The cost of foster care: investing in our children's future*. The Foster Network and BAAF.
- 65 Shared Care Network *Straw poll of shared care providers in Norfolk, Essex, Northern Ireland, Leeds, plus 12 Barnardo's schemes. 4th December 2006*.
- 66 Personal communication with Nicola Smith and Neera Sharma, Policy and Research team, Barnardo's (4 December 2006).
- 67 Personal communication with Sonia Copping, Bradford Metropolitan Borough Council (6 December 2006).
- 68 Robinson, C. (2003) *Short breaks in the South West of England for disabled children and adults with learning disabilities*. South West Learning Disability Network.
- 69 Heslop, P., Byford, S. and Weatherly, H. (2003) *Better Rewards: the cost and effectiveness of employing salaried carers to reduce waiting lists for short-term care*. Shared Care Network, Norah Fry Research Centre and University of York.
- 70 The Children's Trust unit cost data (unpublished) Costs of short breaks for children with severe and complex disabilities.

- 71 **Metcalfe, R.** (unpublished) *An exploration of costing and budgetary processes within the Children's Disability and Health Service. Doncaster Metropolitan Borough Council.* Report for the Managing Health and Social Care Programme, University of Westminster, 2005.
- 72 **Personal communication with Clare Gent,** NCH Service Development Manager, NCH (23 November 2006).
- 73 **Bruns, E.J., and Burchard, J.D.** (2000) *Impact of respite care services for families with children experiencing emotional and behavioural difficulties.*
- 74 **Cowen, P.S., and Reed, D.A.,** (2002) *Effects of Respite Care for Children with Developmental Disabilities: Evaluation of an Intervention for At Risk Families.* Public Health Nursing, 19(4): p. 272-283.
- 75 **Chan, J.B., and Sigafos, J.,** (2001) *Does respite care reduce parental stress in families with Developmentally disabled children?* Child and Youth Care Forum, 30(5).
- 76 **Sherman, B.R.** (1995) *Impact of home-based respite care on families of children with chronic illness.* Children's Health Care, 24: p. 33-45.
- 77 **Rimmerman, A.** (1989) *Provision of respite care for children with developmental disabilities: Changes in maternal stress and coping over time.* Mental Retardation, 27(2): p. 88-102.
- 78 **McNally, S., Ben-Shlomo, Y. and Newman, S.,** (1999) *The effects of respite care on informal carers' well-being: a systematic review.* Disability & Rehabilitation, 21(1): p. 1-14.
- 79 **Hoare, P., Harris, M. Jackson, P. and Kerley, S.** (1998) *A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care.* Journal of Intellectual Disability Research, 42(3): p. 218-227.
- 80 **Botuck, S., and Winsberg, B.G.,** (1991) *Effect of respite on mothers of school-aged and adult children with severe disabilities.* Mental Retardation, 29: p. 43-47.
- 81 **Young, A., Temple, B., Davies, L., Parkinson, G., Bolton, J., Milborrow, W., Hutcheson, G. and Davis, A.** (2006) *Early Support: An Evaluation of Phase 3 of Early Support.* Department for Education and Skills, Research Report 798.
- 82 **Barton, L.** (2006) *Altogether Now: An Evaluation of the Key Working Process in Warwickshire: Professional and Parental Views.* Warwickshire County Council.
- 83 **Sloper, P.** (2005) *National Services Framework: Standard 8. Disabled Children and Young People and Those with Complex Health Needs.*
- 84 **Liabo, K., Newman, T., Stephens, J., and Lowe, K.,** (2001) *A Review of Key Worker Systems for Disabled Children and the Development of Information Guides for Parents, Children and Professionals.* Wales Office of R&D for Health and Social Care.
- 85 **Horrocks, S., Salisbury, C., and Somerset, M.,** (2000) *An Evaluation of the Lifetime Service in Avon.* University of Bristol.
- 86 **East Sussex Local Authority** (2006) *An Evaluation of the Early Support Programme and Care Co-ordination Scheme: Parental and Professional Views.*
- 87 **Hudson, L.** (2005) *Care Coordination Service For 0 To 3's With Complex Care Needs, Luton.*
- 88 **Personal communication with Pam Quilter,** 'Team around the Child' Coordinator for South West Surrey (14 November 2006).
- 89 **Palfrey, J.S., Sofis, L.A., Davidson, E.J., Liu, J., Freeman, L., and Ganz, M.L.,** (2004) *The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model.* Pediatrics, 113(5): p. 1507-1516.
- 90 **Farmer, J.E., Clark, M.J., Sherman, A., Marien, W.E., and Selva, T.J.,** (2005) *Comprehensive Primary Care for Children With Special Health Care Needs in Rural Areas.* Pediatrics, 116: p. 649-656.
- 91 **Witt, W., Kasper, J.D., and Riley, A.W.,** (2003) *Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination.* Health Serv Res, 38: p. 1441-1466.
- 92 **Strickland, B., McPherson, M., Weissman, G., van Dyck, P., Huang, Z.J., and Newacheck, P.,** (2004) *Access to the Medical Home: Results of the national survey of children with special health care needs.* Pediatrics, 113(5): p. 1485-1492.
- 93 **Russell, P.** (2003) *Bridging the gap: the childcare needs of families with a disabled child.* Survey for the Sure Start Unit, available from the Council for Disabled Children.
- 94 **Office for National Statistics** (2006) *Annual Survey of Hours and Earnings (ASHE) - 2006 results.* Table 1: All employees.
- 95 **Office for National Statistics** (2004) *Annual statistics on population and family structure.*
- 96 **Ofsted** (2003) *Annex 2: Pupils with emotional, behavioural and social difficulties in mainstream schools: Special educational needs in the mainstream.*
- 97 **Fisman, S., Wolf, L., Ellison, D., and Freeman, T.,** (2000) *A Longitudinal study of siblings with chronic disabilities.* The Canadian Journal of Psychiatry, 45: p. 369-375.
- 98 **Breslau, N., Weitzman, M., and Messenger, K.,** (1981) *Psychologic functioning of siblings of disabled children.* Pediatrics, 67: p. 344-353.
- 99 **Williams, P.** (1997) *Siblings and pediatric chronic illness: a review of the literature.* International Journal of Nursing Studies, 34: p. 312-323.
- 100 **Department for Education and Skills** (2006) *Statistical First Release: Special Educational Needs in England, January 2006.*
- 101 **Dockrell, J.E., Peacey, N. and Lunt, I.** (2002) *Literature Review: Meeting the Needs of Children with Special Educational Needs.* Institute of Education, University of London.
- 102 **Department for Education and Skills** (2005) *National Curriculum Assessment, GCSE and Equivalent Attainment and Post-16 Attainment by Pupil Characteristics, in England 2005.*
- 103 **Godfrey, C., Hutton, S., Bradshaw, J., Coles, B., Craig, G., and Johnson, J.,** (2002) *Estimating the cost of being "not in education, employment or training" at age 16-18.* DFES Research Report RR346.
- 104 **Catalano, R., and Dooley, D.,** (1983) *The Health Effects of Economic Instability: A Test of Economic Stress Hypothesis.* Journal of Health and Social Behavior, 24: p. 24-60.

- 105 Mind (2005) *Stress and Mental Health in the Workplace*.
- 106 Carmichael, F., and Charles, S., (1998) *The labour market costs of community care*. *Journal of Health Economics*, 17: p. 747-765.
- 107 Office for National Statistics (2006) *Labour Market Trends*.
- 108 Office for National Statistics (2001) *General Household Survey*.
- 109 SEN Regional Partnerships (2004) *Analysis of out of authority placements 2004*. DfES, SEN Regional Partnerships.
- 110 Office for National Statistics website, http://www.hm-treasury.gov.uk/economic_data_and_tools/gdp_deflators/data_gdp_fig.cfm [accessed on 11 December 2006].
- 111 Haskey, J. (1996) *Population Trends: Divorce and Children*. *Population Trends* 84.
- 112 Rent Right website, http://www.rentright.co.uk/00_00_00_1_00_rrpi.aspx [accessed on 25 January 2007].
- 113 Norwich Union website, <http://www.aviva.com/index.asp?PageID=44&year=&newsid=2935&filter=UKLIFE> [accessed on 25 January 2007].
- 114 Office for National Statistics (2007) *News Release: Housing-related costs average £140 a week. Family spending 2006 - results of the Expenditure and Food Survey 2005/06*.
- 115 Social security (DLA) regulations 1991 SI: 1999/2890, http://www.opsi.gov.uk/SI/si1991/Uksi_19912890_en_1.htm.
- 116 Social Security Contributions and Benefits Act 1992, Disability Living Allowance, Sections 71-76, http://www.opsi.gov.uk/ACTS/acts1992/Ukpga_19920004_en_4.htm#mdiv71.

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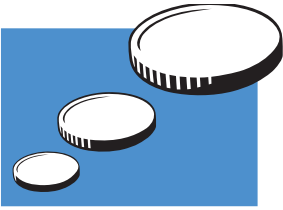
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