



contact a family
for families with disabled children

Counting the costs

Introduction

Contact a Family is a national charity providing support, information and advice to parents with disabled children, no matter what the disability or condition.

Each year Contact a Family reaches out to 300,000 families with a disabled child. We run a national freephone helpline, organise events and workshops locally, produce a medical directory with information on over 1,000 disabilities and rare conditions and put families in touch with others so they can benefit from their mutual support and understanding. Last year there were 1.8 million visits to Contact a Family's website www.cafamily.org.uk

This report describes the findings of an online survey carried out during the summer of 2008 (May-July) with 793 UK parents of disabled children about their economic situation over the last 12 months.

It costs three times as much to raise a disabled child¹. This is due to direct extra costs such as aids, adaptations, transport, heating and childcare. And disabled children and their families are at greater risk of living in poverty².

With prices for every household rising in the UK due to soaring fuel and food costs, Contact a Family wanted to see how families with disabled children were being affected by the recent economic downturn.

1. Paying to Care: the costs of childhood disability by Barbara Dobson and Sue Middleton (Joseph Rowntree Foundation 1998).

2. Households Below Average Income Figures 2006/07 (Department of Work and Pensions). Showed the risk of relative poverty for families with a disabled child but no disabled adult family member has increased from 20% to 25%, meaning disabled children are now at greater risk of living in relative poverty than non-disabled children.

“ The main costs with Emma are the clothes because she dribbles constantly. She can't feed herself as her coordination is impaired and she can't drink from a glass without spilling everything. I must admit, I don't have the money to buy her clothes all the time to replace those that are stained. I am lucky because my Mum helps out. ”

Counting the Costs - financial situation for families with a disabled child in the UK, overview

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1. Going without

The survey's findings show that, due to a lack of money, 1/6 of families with disabled children are going without on essentials such as food and heating.

More expensive items such as adaptations to the home are unaffordable for more than 1/3 of families. Adaptations can be anything from widening doors for wheelchair access, to building a downstairs bedroom and bathroom to save family carers from having to carry a severely disabled child up and down stairs.

And items that other families take for granted such as holidays and days out are unaffordable for almost 2 out of 3 families with a disabled child.

In the last 12 months, because of a lack of money, have you had to go without any of the following items?	Yes	Percentage
Adaptations	302	38%
Clothes	343	43%
Toys	207	26%
Bedding	183	23%
Food	126	16%
Heating	128	16%
Leisure	376	48%
Days Out	486	61%
Holidays	505	64%
Other	186	23%

“ Because of his disability everything costs more: washing powder, running the washing machine and equipment like his bath, toilet and bed because they all use electricity. Even his toys are more expensive because you have to think of his ability and how it can be accommodated. I often think how simple life would have been if he was not disabled – just one school for my kids, holidays abroad. But I love my Joe to bits. He is a happy go lucky boy, has a funny sense of humour and is always smiling. ”

2. Arrears

One in five families with a disabled child is struggling to keep up with mortgage repayments. This can be the start of a downward spiral towards repossession and homelessness.

The most common financial problem is keeping up with credit card payments - more than 1 in 3 are failing to do so.

Families are under enormous practical, physical and emotional pressures, with more than half reporting that caring for a disabled child has caused some or major difficulties in their relationship³. And of those, 66% perceived the cause of family breakdown or relationship difficulties was due to finances⁴. The added stress of falling behind with mortgage, council tax or credit card payments, could have serious implications for family relationships.

In the last 12 months have you ever got into arrears with any of the following?	Yes	Percentage
Utilities	225	28%
Council Tax	184	23%
Mortgage/Rent	142	18%
Credit Cards/Loans	298	38%
Other	146	18%

3. Contact a Family survey – No Time for Us, Relationships between parents who have a disabled child. Of 2,000 parents surveyed 53% believed having a child with a disability had caused either ‘some’ or ‘major’ difficulties or the breakdown of the relationship.

4. Contact a Family survey – No Time for Us, Relationships between parents who have a disabled child. 66% of 2,000 parents believed that their financial difficulties were linked to having a disabled child.

“ Our house had to be sold to a housing association on a shared ownership basis so that we could stay in the house which has a £35,000 adaptation extension put on it for Joe. This incurred court costs which have now been attached to the house as a “Charge” through the courts – around £15,000. If my son was not disabled we would have been able to sell this house and move away. ”

3. Court Action

One in 14 families with a disabled child reported that they have been threatened with court action for failing to keep up with their mortgage repayments. This is one of the final stages of home repossession and being made homeless.

The council of Mortgage Lenders (CML) reported (August 08) there are

11.8 million mortgages currently being paid off in the UK. In 2007 there were 27,100 repossessions – 0.23%. The CML predicts that in 2008 there will be 45,000 repossessions – 0.38%.

On 5th August 2008 the Financial Services Authority (FSA) said that mortgage lenders were focusing too strongly on recovering arrears and were too quick to take court action. It urged banks and building societies to be flexible, to make sure they consider customers' individual circumstances and to use court action as a last resort.

In the last 12 months have you been threatened with court action for failing to keep up with payments for the following?	Yes	Percentage
Utilities	39	5%
Council Tax	100	13%
Mortgage	57	7%
Credit Cards/Loans	133	17%
Other	65	8%

“ And of course there is the cost involved with all the trips to the hospital for the numerous tests she has to be checked for (audio tests, video fluoroscopy...) and petrol is not cheap nowadays and the parking at the hospital – it all adds up. ”

4. Charity Help

A quarter of families with a disabled child have applied for financial assistance from a charity in the last 12 months. The majority of applications were for money towards a holiday, followed closely by therapies and clothes.

In the last 12 months have you applied for a charity grant or approached a charity for funding?	Yes	Percentage
Yes	202	25%
If so what for?		
Household Goods	53	7%
Adaptations	34	4%
Therapies	79	10%
Clothes	80	10%
Toys	38	5%
Bedding	52	7%
Food	15	2%
Heating	8	1%
Leisure	40	5%
Holidays	117	15%
Other	63	8%

“ Callum has the needs of a new born baby, he is doubly incontinent and often sick so the washing machine and dryer are always on. Callum’s lack of mobility means he doesn’t generate his own heat, so the house has to be very warm to make him comfortable. This means our gas and electricity bills are unavoidably sky high. ”

5. Loan

More than 1 in 4 of families with disabled children who took part in the survey had taken out a loan in the last 12 months.

Have you ever taken out a loan in the last 12 months?	Yes	Percentage
Yes	209	26%
If so what for?		
Household Goods	42	5%
Adaptations	39	5%
Therapies	24	3%
Clothes	65	8%
Toys	50	6%
Bedding	43	5%
Food	34	4%
Heating	44	6%
Leisure	42	5%
Holidays	48	6%
Other	112	14%

“ The general wear and tear on the house if you have a dyspraxic and autistic child is far higher and that increases as they get older because they are bigger and stronger. We get through a whole dinner service every year because of breakages! ”

6. Borrow

Almost half of families with disabled children have to resort to borrowing from their friends and families due to a lack of funds. This money is often used to pay for basics: almost 1 in 5 borrowed money to pay their heating bills and almost a quarter used it to help pay for adaptations to their home.

Have you borrowed money from friends and family in the last 12 months?	Yes	Percentage
Yes	330	42%
If so what for?		
Household Goods	76	10%
Adaptations	178	22%
Therapies	42	5%
Clothes	32	4%
Toys	110	14%
Bedding	58	7%
Food	52	7%
Heating	154	19%
Leisure	131	17%
Holidays	104	13%
Other	152	19%

“ What makes me angry is I have no choice as to what we can do with our lives now, our future looks bleak on the benefit system. We are trapped in a benefit trap. ”

7. Future Forecast

Almost half of families with disabled children envisage their financial situation worsening in the next 12 months. Only 7% were optimistic things would improve.

How do you see your financial situation in the next 12 months?	Yes	Percentage
Improving	59	7%
Same	321	40%
Worse	370	47%

“ My son is 20 months old and has a rare form of Achondroplasia and is oxygen dependent. Since he came home from hospital last August our utility bills have gone through the roof. He needs two Portable Oxygen Concentrators and has humidified oxygen via an electric machine as well. We pay over £400 per quarter on electricity and have arrears of over £700. Air Products pays us £86 per quarter to help, as they say this is how much electricity the machines use. We have been unsuccessful in getting funding to clear the debt, therefore miss out on a lot of things. We were not in debt before our son came home. ”

Counting the Costs – Key survey findings by disabled child’s age

1. Where the child is aged 0 to five (271 respondents)

Going without

In the last 12 months have you ever had to go without any of the following due to lack of funds?	Yes	Percentage
Food	39	14%
Heating	40	15%

Arrears

In the last 12 months have you ever got into arrears with the following?	Yes	Percentage
Mortgage/Rent	52	19%

Court Action

In the last 12 months have you been threatened with court action for failing to keep up with payments for the following?	Yes	Percentage
Mortgage	18	7%

“ I’m in arrears with all my bills. Credit cards have been used for food shopping and paying bills. I manage to keep up with the mortgage but utility bills have accumulated. Gas arrears means I have now stopped using it while I try to get on top of the debts. Other domestic bills are all red letters. I have to negotiate who to pay on which month, depending who is threatening to cut me off. ”

Charity help

In the last 12 months have you applied for a charity grant or approached a charity for funding?	Yes	Percentage
Yes	65	24%
If so what for?		
Food	5	2%
Heating	2	1%

Borrow

Have you borrowed money from friends and family in the last 12 months?	Yes	Percentage
Yes	118	44%
If so what for?		
Food	25	9%
Heating	55	20%

How do you see your financial situation in the next 12 months?

How do you see your financial situation in the next 12 months?	Yes	Percentage
Worse	121	45%

“ We’ve had to increase our mortgage considerably to pay for the adaptations which ensure Anthony can get around the house in his wheelchair or using walking aids. ”

2. Where the child is aged six to 12 (327 respondents)

Going without

In the last 12 months have you ever had to go without any of the following due to lack of funds?	Yes	Percentage
Food	53	16%
Heating	51	15%

Arrears

In the last 12 months have you ever got into arrears with the following?	Yes	Percentage
Mortgage/Rent	60	18%

Court Action

In the last 12 months have you been threatened with court action for failing to keep up with payments for the following?	Yes	Percentage
Mortgage	27	8%

“ Due to lack of resources at school, speech and language therapy for my son is only available privately. Because I couldn't possibly afford it, Sam misses out, even though it is an identified need. If I wasn't so much in debt I would gladly pay for the extra help that is required. Often children with disabilities who do well are the ones whose parents can afford the extra input and social activities. ”

Charity help

In the last 12 months have you applied for a charity grant or approached a charity for funding?	Yes	Percentage
Yes	92	27%
If so what for?		
Food	7	2%
Heating	4	1%

Borrow

Have you borrowed money from friends and family in the last 12 months?	Yes	Percentage
Yes	138	41%
If so what for?		
Food	18	5%
Heating	73	22%

How do you see your financial situation in the next 12 months?

How do you see your financial situation in the next 12 months?	Yes	Percentage
Worse	157	47%

“ Sam can't go on the bus or train or to the swimming pool unaccompanied, so even if just one of us needs or wants to go somewhere we have to pay double. ”

3. Where the child is aged 13-19 (195 respondents)

Going without

In the last 12 months have you ever had to go without any of the following due to lack of funds?	Yes	Percentage
Food	40	20%
Heating	46	23%

Arrears

In the last 12 months have you ever got into arrears with the following?	Yes	Percentage
Mortgage/Rent	36	18%

Court Action

In the last 12 months have you been threatened with court action for failing to keep up with payments for the following?	Yes	Percentage
Mortgage	16	8%

“ I am extremely worried for the future as all of my monthly salary seems to be absorbed in paying arrears. There is never any money left to go round and that's on a council professional salary. Being a single parent adds to the financial stress as the responsibility lies solely with one person. ”

Charity help

In the last 12 months have you applied for a charity grant or approached a charity for funding?	Yes	Percentage
Yes	46	23%
If so what for?		
Food	8	4%
Heating	7	4%

Borrow

Have you borrowed money from friends and family in the last 12 months?	Yes	Percentage
Yes	76	38%
If so what for?		
Food	15	8%
Heating	36	18%

How do you see your financial situation in the next 12 months?

How do you see your financial situation in the next 12 months?	Yes	Percentage
Worse	99	50%

Conclusions and recommendations

Contact a Family Counting the Costs Survey findings provide evidence that families with disabled children are under enormous financial pressure in the worsening economic crisis.

Families with disabled children aren't just missing out on holidays and days out, they are struggling to meet payments for household bills, rent and mortgages. Some families are finding it so tough that they are going without food. And many are borrowing money from friends or family, seeking charitable help or taking out loans to keep afloat financially. Families with disabled children are continuing to live in unsuitable accommodation as many report going without the necessary adaptations to their homes. And despite grants being available to cover costs of adaptations, many families have to borrow money from friends and family to make up the cost.

Families with disabled children are more likely to be adversely affected by an economic downturn because they are at greater risk of living in poverty.

Families with disabled children face two specific financial challenges in addition to those faced by all families. They incur considerable additional and ongoing costs caring for their child. And there are difficulties sustaining employment due to the demands of caring and cost of childcare for a disabled child.

Contact a Family fully supports the End Child Poverty campaign calling on government to invest the necessary resources and policy changes to deliver on its promise to eradicate child poverty in the UK by 2020.

The key benefit designed to meet some of the additional costs faced by families with disabled children is Disability Living Allowance. To reduce the higher risk of poverty for disabled children, Contact a Family would like to see the government uplift DLA significantly to come closer to meeting the real additional costs of bringing up a disabled child. Disability Alliance has estimated that an uplift in the region of 30-50% would come close to achieving this.

More than half of families with disabled children are not claiming Disability Living Allowance. Take up among ethnic minority families is particularly low.

Contact a Family urges the government to undertake a DLA take-up campaign with a particular focus on ethnic minority families.

Contact a Family would also like to see an extension of winter fuel payments to parents of disabled children. Some of these families have great difficulty getting out and about in winter so stay indoors. And many have children whose condition worsens in the cold weather. As a result families unavoidably have their heating on constantly in the winter months. There needs to be a targeted benefit like the Winter Fuel Payment paid to help families at these times, particularly in light of recent price hikes by the major energy companies.

Contact a Family urges government to consider a significant uplift of Carer's Allowance. We also call for a general review of the benefit altogether, with a particular focus on the bar to full-time study, the need to taper the reduction as carers take on work and the need to increase payments for those caring for two or more dependants.

Contact a Family is one of the four founding members of Every Disabled Child Matters, the campaign to get rights and justice for disabled children. Contact a Family supports EDCM's recommendations to improve the housing situation for families with disabled children in their campaign briefing Disabled Children and Housing.

Contact a Family will continue to raise awareness among families of their financial rights and entitlements - and help them, through our national freephone helpline and team of family workers, to maximise their incomes.

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