

contact a family
for families with disabled children



Counting the Costs 2010

The financial reality for families
with disabled children

Contact a Family provides advice, information and support to all UK families with disabled children regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspect of raising a disabled child, including help with finances, benefits and debt issues. We have a welfare rights team, which helps to generate much needed extra income for families.

About the survey

Counting the Costs 2010 was carried out between February and April 2010 and completed by 1,113 UK respondents. All respondents are parents of disabled children:

- 224 have a disabled child aged 0 to 5
- 549 have a disabled child aged 6 to 12
- 340 have a disabled child aged 13 to 19.

Counting the Costs 2010 was an online survey made up of open and closed questions. It is a repeat of a survey carried out by Contact a Family in 2008 and the same questions have been used to enable comparison. However additional questions were added to the 2010 survey. We added questions on the benefits system, working and childcare.

Contact a Family would like to thank all the families with disabled children who completed our survey.

Written by Elaine Bennett.

Cash Counts is Contact a Family's one-stop shop for benefits advice and money tips for families with disabled children.

Cash Counts includes:

- An online benefits calculator, allowing families to work out how much they are entitled to
- A top tips guide on the benefits available to families with disabled children written by the Contact a Family helpline
- A frequently asked questions page to help families navigate the complex benefits system.

<http://www.cafamily.org.uk/cashcounts>

Summary

Families with disabled children are living under extreme financial pressures.

The UK has just experienced the worst recession since the 1930s and the economic outlook is still unclear. Everyone has been feeling the pinch and some have been financially devastated by recent rising living costs, rising unemployment and poor interest on savings.

Families with disabled children have always had financial difficulties. This is due to a catastrophic combination of the extra costs of raising a disabled child and the difficulty of holding down a job, as well as caring. Many families are forced to live on benefits.

“I do not know how to describe the hell that is imposed on us as a family due to financial worries. It impacts on every single aspect of our lives. People complain about the ‘economic situation’ but the reality for us is that nothing has really changed.”

Research shows that families with disabled children are more likely to be living in poverty than other families¹. They face practical, physical and emotional challenges over and above families with non-disabled children and money worries can push some to breaking point.

Counting the Costs 2010 describes the findings of an online survey completed by 1,113 parents of disabled children in the UK. Contact a Family conducted the survey to find out the impact of the recession on families who were already vulnerable to money difficulties.

It is a repeat of a survey carried out in 2008 when the economic downturn was in its early stages. *Counting the Costs 2010* reveals that families with disabled children are living under extreme financial hardship. Many aspects of their financial situation are worsening.

1. Department of Work and Pensions (2006-7) Households Below Average Income found that the risk of living in poverty for families with disabled children has increased from 20-25% making disabled children at greater risk of living in relative poverty than non-disabled children.

“I have suicidal thoughts over the amount of debt we have sunk into. I can’t see our situation ever improving. Friends think I am strange for not meeting in cafes. A cup of tea is the equivalent of two hours Carer’s Allowance.”

Families with disabled children were already facing huge financial pressures before the recession and these challenges have been exacerbated by the economic slump. These pressures can have a devastating impact on family life, relationships and health.

Key findings

Our survey of over 1,100 families with disabled children shows:

- Almost a quarter (23%) are going without heating. This is up from 16% in 2008.
- Almost three quarters (73%) are going without leisure and days out. This is up from 55% in 2008.
- One in seven (14%) are going without food. This is a slightly better picture than in 2008, when one in six reported going without food.
- More than a third (34%) have fallen behind with repayments, mostly for credit cards or loans.
- More than half (51%) have borrowed from family or friends to keep financially afloat or pay for essentials. This is up from 42% in 2008.
- Almost half (42%) have applied for a charity grant. This is up from 25% in 2008.
- Almost 90% said that financial worries had a detrimental impact on their family life.

Recommendations

To help families get back into work

- We call on the UK Government to increase the earnings disregard for carers claiming means-tested benefits, such as Income Support, Housing Benefit and Council Tax Benefit.
- We call on the UK Government to increase the earnings limit for Carer's Allowance and taper it so that the entire allowance is not lost when earnings go above the limit.
- We call on the UK Government to develop the Employment Act 2002 by creating a right to insist on flexible working arrangements for parents of disabled children, unless a clear business case exists to reject such a request. This right should not be subject to any qualifying period of employment for parents of disabled children, as is currently the case.
- We call on the UK and devolved Governments to look at ways of making childcare more affordable for families with disabled children.

To ensure families are getting their benefits entitlements

- We call on the UK Government to act quickly to simplify the benefits system. In particular we welcome the intention to introduce a new simplified Disability Living Allowance (DLA) form for children, currently being piloted by the Department of Work and Pensions. We look forward to seeing the evaluation of this pilot and if successful, urge a quick national roll out.



To reduce fuel poverty

- We call on the UK Government to pilot the extension of a Winter Fuel Allowance of £200 to families with disabled children under five, who are in receipt of DLA at the middle or higher rate of the care component, and/or the higher rate of the mobility component.
- We call on the UK Government to make Cold Weather Payments available to all families with disabled children in receipt of DLA.
- We call on UK energy companies to offer social tariffs and promote the use of the priority register to families with disabled children, as well as include them in their schemes for "vulnerable customers".
- We call on the UK Government to put pressure on energy companies to make social tariffs available to families with disabled children in receipt of DLA, using its new powers under the Energy Act 2008.
- The eligibility criteria of the Government funded heating and insulation schemes in England (Warm Front) and Northern Ireland (Warm Homes) should include families with disabled children in receipt of DLA in line with those in Scotland (Energy Assistance Package) and Wales (Home Energy Efficiency Scheme).

To reduce debt

- We call on all UK frontline services to effectively signpost families with disabled children to specific debt advice services and to those services offering advice on income maximisation, such as Contact a Family.
- We call on all UK services providing debt advice and information to be trained in the unique financial challenges that families with disabled children face.

To reduce isolation

- Local authorities should ensure that their offer of leisure activities is affordable and accessible for families with disabled children.
- The devolved Governments should make funding available for a transformation of services and support for families with disabled children in the next Spending Review.

Survey results

Going without essentials

“You try to do what’s right by your child, give them the food instead of yourself. She’s had one chest infection after another because we have no central heating and it costs too much to put on the oil filled heater.”

In the last 12 months, have you had to go without any of the following, because of a lack of money?	Yes	%
Food	158	14%
Heating	251	23%
Childcare	243	22%
Leisure/days out	807	73%
Holidays	754	68%
Adaptations	277	25%
Clothes	493	51%
Toys	267	28%
Bedding	187	19%
Answered question	965	87%
Skipped question	148	13%

Our survey of over 1,100 families with disabled children shows:

- Almost a quarter (23%) are going without heating.
- One in seven (14%) are going without food.

“When the children have gone to bed, I turn off all the lights to save electric.”

As in 2008, families with disabled children are not just missing out on luxuries, they are also cutting back on basics.

More families – 7% – are now going without heating than two years ago. Lack of heating in a household with a disabled child can have serious health risks. Many disabilities and health conditions worsen in the cold weather and heating is necessary to prevent a child becoming ill and in some cases hospitalised. There are many families who can’t get out the house during winter months so heating is even more essential for them.

To reduce the above average risk of families with disabled children living in fuel poverty, we call on the UK Government to pilot the extension of a Winter Fuel Allowance of £200 to families with disabled children under five, who are in receipt of DLA at the middle to higher rate of the care component and/or the higher rate mobility component. We estimate the maximum annual cost of this pilot scheme would be £8.9 million to benefit 44,710 families.

We also call on the UK Government to make Cold Weather Payments available to all families with disabled children in receipt of DLA.

We urge UK energy companies to recognise families with disabled children as vulnerable customers, to protect them from disconnection and make available schemes which can help with fuel debt, including grants and social tariffs offering discounts on energy bills.

“The children have never gone without, but me and husband have gone without food before.”

One in seven families are going without food. Although this is a slight decrease from one in six families in 2008, it is alarming that families caring for a disabled child are forced to go without the most fundamental of basic needs. It is apparent from written responses that parents are going without to ensure their children have enough.

“I went without food to pay for some damage that my son had done to a car.”

Social isolation

“All I want is for my child to have the same opportunities as other kids who don't have disabilities. A day out for us must include the cost of care worker support, which adds at least £100 to any trip. Holiday? How?”

Our survey of over 1,100 families with disabled children shows:

- Almost three quarters (73%) are going without leisure and days out. Up from 55% in 2008.
- 68% are going without holidays.

Families with disabled children are often socially isolated and this is made worse by a lack of money. Many can't afford to have a social life and the survey reveals that more families are going without days out than in 2008 when the recession began to bite.

Leisure and days out cost more for families with disabled children and they have to bear that additional cost. Even the most basic leisure activities that other families take for granted, such as swimming or going to the park, can be unaffordable. A family may require a care worker for support or may need to drive everywhere to transport their child's equipment, so incur care or petrol costs when they go out.

“It is very hard to explain to other children why days out and holidays are not on the agenda and hope that having to go without doesn't lead to more resentment towards their disabled sibling.”

Research shows that lack of leisure activities and days out leads to poor well-being and health as well as pressure on family relationships.

“We have only had two holidays in the last 16 years, the last one was 10 years ago. I have not had a break from caring, not a single day, since 2006.”

We urge local authorities in the UK to ensure that their offer of leisure activities is affordable and accessible for families with disabled children.

We welcome the UK Government's recognition of the importance of short breaks with the recent announcement of an extra £20million funding, and look forward to hearing further plans. We call on the devolved Governments in Scotland, Wales and Northern Ireland to make funding available for a transformation of services and support for disabled children and their families in the next Spending Review.



In debt

“I have fallen into the trap of having a loan from a doorstep loan company, my interest rate is 399% but I could not get one anywhere else, as I sold my gold last year.”

In the last 12 months, have you fallen behind with payments for any of the following?	Yes	%
Utilities	327	29%
Council Tax	170	15%
Mortgage/rent	160	14%
Credit cards/loans	380	34%
Other	56	5%
Answered question	580	52%
Skipped question	533	48%

Our survey of over 1,100 families with disabled children shows:

- More than a third (34%) have fallen behind with repayments, most for credit cards and loans as well as utility bills.
- Of those who fell behind with payments, 65% were threatened with court action for council tax arrears, 43% for mortgage/rent arrears, 40% for utility bills arrears and 38% for credit cards/loans arrears.
- There’s a significant increase in families being threatened with court action for falling behind with council tax and utility bills arrears in the last two years. The number of families being threatened with court action for credit cards/loans arrears has decreased.
- Over 25% have taken out loans – three quarters of those have used the loan to pay off other debts (75%).

“It is frightening, because we go without food heating and car fuel, even keeping the children off school, as cannot afford to pay for fuel for the car. I just know that I have to pay the bills first or they would just keep mounting up.”

Families with disabled children are more likely to be living in poverty. Affording living costs is a struggle for many and the survey reveals that one third (34%) are falling behind with payments. It will take these families, many who are

on low incomes or reliant on benefits, numerous years to pay back these debts. Research shows that being in debt and financial worries can have a devastating impact on family relationships, quality of life and health.

“Our debt frightens me, it is a constant source of stress and anxiety, it makes me feel ill, and of course the creditors are not willing to listen, they just want money, whether you can afford the repayments or not. I can’t afford to repair my car at the moment so the family is really having a hard time.”

If you answered yes to borrowing money from family and friends in last 12 months, what was it for?	Yes	%
Food	230	43%
Heating	169	31%
To pay off other debts	142	26%
To pay rent/mortgage	83	15%
Household goods	146	27%
Leisure/days out	61	11%
Holidays	42	8%
Adaptations	26	5%
Equipment for your disabled child	60	11%
Therapies	57	11%
Clothes	96	18%
Toys	39	7%
Bedding	40	7%
Other	65	12%

More than half of families with disabled children have borrowed money from family and friends to keep financially afloat or buy essentials. Of those, 40% borrowed money to buy groceries and 30% to pay heating bills.

“My money is not lasting because of the amount I put in my gas and electric meters. I need to borrow money at least once a fortnight to keep my son warm and for food.”

Borrowing from family and friends doesn't have the financial dangers of taking out a loan with astronomical interest rates, but there is an emotional pressure attached. Families with disabled children will struggle to repay borrowed money and this adds to the strain they are under.

"It's very embarrassing when you have to go cap in hand to members of family."

We call on all UK frontline services to effectively signpost families with disabled children to specific debt advice and to those services offering advice on income maximisation, such as that provided by Contact a Family. All services providing debt advice and information should be trained to understand the unique financial challenges that families with disabled children face.

Charity grants

Our survey of over 1,100 families with disabled children shows:

- More than 40% have applied for a charity grant in the last year. This is up from 25% in 2008.

More families with disabled children are applying for charity grants. It is unclear if there is more demand or if the grants are better publicised and more accessible. The majority of applicants (80%) were successful in getting the grant and most used the financial help to put towards a holiday (33%) or household goods (25%). Many received a grant for equipment (15%) such as wheelchairs, specialist car seats and beds.

Working and childcare

"I tried to carry on working full time, and caring for all three children, but the stress of everything led me to have a nervous breakdown. Now I'm not allowed to work more the 12 hrs a week, how I'm going to cope, I'll never know!!!! All because, there's not enough help for us carers!!!"

Our survey of over 1,100 families with disabled children shows:

- 40% work and 60% don't.
- 45% of families with disabled children are paying more for childcare for their disabled child.

Many parents of disabled children wish to return to work in order to lift their families out of poverty. However, it is currently very difficult for parents of disabled children to find and maintain regular work due to their caring responsibilities.

Currently you only have the right to request flexible working after 26 weeks in employment. Flexible working is an essential pre-condition of work for parents of disabled children and they need this from the start of their employment.

We call on the UK Government to develop the Employment Act 2002 by creating a right to insist on flexible working arrangements for parents of disabled children, unless a clear business case exists to reject such a request. This right should not be subject to any qualifying period of employment for parents of disabled children, as is currently the case.

There needs to be greater support into employment for families with disabled children who are able to work, including changing benefits rules which currently act as a disincentive. We call on the UK Government to increase the earnings disregard for carers claiming means-tested benefits, such as Income Support, Housing Benefit and Council Tax Benefit.

We also urge the UK Government to increase the earnings limit for Carer's Allowance. In addition the Government should taper the earnings limit, so that the entire Carer's Allowance is not lost when earnings go above the limit.

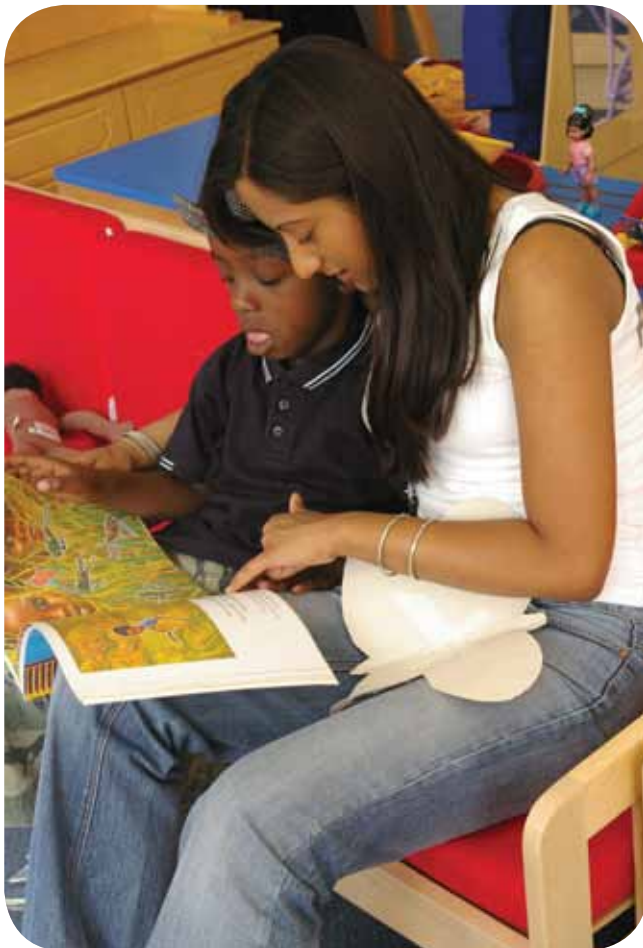
"I found over the years that childcare provision for children like mine is virtually non-existent. I found a lady in my area who charged three times the normal rate for after school childcare for children with special needs. I left work due to the demands of my son's condition and found when I tried to return to work that childcare costs outstripped my take home pay. I feel that I have no way out of the financial trap I am in."

The survey reveals that a high number of families are being charged more for childcare simply because their child is disabled. This is another illustration of the extra costs for families with disabled children and shows that families are being forced to bear these additional costs.

Childcare provision can facilitate parental employment, helping to move families out of the poverty trap and reduce stress. We call on the UK and devolved Governments to urgently look at ways of making childcare more affordable for families with disabled children.

The benefits system

“As a full time carer, I feel that Carer’s Allowance is an insult for what we do. This lack of money makes it impossible to make ends meet. It is frightening stressful and degrading to be put in this situation and beyond my control.”



Our survey of over 1,100 families with disabled children shows:

- 95% are claiming Disability Living Allowance (DLA) for their child.
- Almost 80% find the benefits system difficult or fairly difficult to navigate.
- 34% found out about DLA, the major benefit available to families with disabled children, from another parent.

DLA is the major benefit to help cover the extra costs of raising a disabled child and it is positive to see that most respondents are claiming this financial help. DLA not only helps towards additional costs, it is also a gateway to other benefits including Carer’s Allowance, so it is vital that families with disabled children are accessing this existing help.

A large proportion of families (34%) found out about DLA from another parent rather than a professional or statutory authority. It is worrying that parents are finding out about financial help in such an unstructured way as there is the risk that they will go without for years. We call on all UK frontline services to effectively signpost families with disabled children to specific and targeted benefits advice provided by organisations such as Contact a Family.

The survey reveals that families with disabled children overwhelmingly find the benefits system complex and difficult to navigate. To ensure that families with disabled children are getting the major benefit available to them to reduce their above-average risk of living in poverty, we call on the UK Government to act quickly to simplify the benefits system. In particular we welcome the intention to introduce a new simplified DLA form for children, currently being piloted by the Department of Work and Pensions. We look forward to seeing the evaluation of the pilot and if successful, urge a quick national roll out.

Financial worries

"When things get as bad as they are and you have the threat of losing your home, I felt I was letting my family down hugely. I have spent the last 19 years in my house only to provide stability for my children, to then think you are going to lose this, the worry factors are great, even enough to contemplate suicide."

Our survey of over 1,100 families with disabled children shows:

- Almost 90% said that financial worries had a detrimental impact on their family life.
- 43% think their financial situation will get worse in the next 12 months. There was a similar picture in 2008.

"My marriage has failed partly due to financial pressures and worries, as well as the impact of having a disabled child... so yes, financial worries have had a detrimental effect."

Financial worries clearly have a negative impact on family life and 90% of respondents said that they had experienced this distress. Families coping with many challenges and making an enormous contribution to society should not have to cope with this additional strain.

"Each month I do not have enough money to cover my outgoings. My husband and I are very stressed. My other children are suffering. It would be so easy to walk away and say to social services, go ahead and take my daughter, but that would finish me off"

Looking to the future, 43% of respondents feel that their economic situation will worsen. The cause of their concern was the expenses associated with their disabled child (52%), the difficulty of working and being a carer (52%), the economic climate (43%) and family circumstances changing (27%).



Conclusion

"I went bankrupt this year as the situation was unbearable. There needs to be more advice out there and more regulations for companies who you have debts with if you have a disabled person in the household."

Counting the Costs 2010 shows that families with disabled children continue to live under enormous and disproportionate financial pressure. Families with disabled children aren't just missing out on life's luxuries, but are going without essential basics, such as food and heating. Many are reliant on benefits and many are forced to borrow from family and friends or seek charity handouts.

We welcome the Child Poverty Act 2010, which enshrines in law the Government's target to eradicate child poverty in the UK by 2020. We urge that the strategies to come out of the Act consider the unique challenges for families with disabled children, such as those clearly identified in this report, and devise targeted support for these families.

We urge the Government to honour their commitment to "protect the most vulnerable in society". In developing the Comprehensive Spending Review, we would ask the Government to pay particular attention to families with disabled children who are amongst the poorest and most vulnerable in our society.

We are encouraged that disabled children will form one of the focuses on the newly announced Childhood and Families Taskforce and hope it will look at all issues affecting families with disabled children.

"We were we told our house was wholly unsuitable for our son and could not be adapted. We had to sell and stretch ourselves from just over 3.5 times my husband's salary to 4.5 times - we are now facing financial ruin. We have both worked hard all our lives to afford what we have and due to our circumstances now it is all slipping away from us."

Research shows that financial worries impact greatly on a family's well being, quality of life, relationships and ultimately their health.

Families with disabled children are already under enormous practical, physical and emotional pressures. They are making an enormous contribution to society which often goes unrecognised and unrewarded.

Contact a Family believes families with disabled children should not have to live under these additional pressures due to money worries. We call on all Governments to recognise these pressures and act quickly to reduce their disproportionate financial burdens. It is vital that all Governments recognise these pressures and act quickly to reduce their disproportionate financial burdens. It is also imperative that all energy companies offer schemes and assistance packages to families with disabled children to reduce their risk of living in fuel poverty. And frontline services must recognise the unique financial challenges that families with disabled children face and signpost them to specialist benefits and debt advice services. This will help families with disabled children to lead the ordinary lives they have a right to lead.

About Contact a Family

Campaigning

We campaign for rights and justice for all families with disabled children.

Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking site or using our one-to-one linking service.

Medical information

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 1200 conditions and related support. Each entry provides an overview of the condition with details of support groups where available.

One-to-one support

We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

Getting in contact with us

Helpline 0808 808 3555

Web: www.cafamily.org.uk

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