Counting the Costs 2014

Research into the finances of more than 3,500 families with disabled children across the UK
Our Counting the Costs 2014 Survey Found

Families with disabled children are going without the basics

Some are going without food and heating more than once a month. Some children are even going without specialist equipment, therapies and hospital appointments.

This isn’t something new, but it’s getting worse

The number of families going without food has doubled in the last two years. Nearly a third of families with disabled children are going without heating. The impact for many is debt, stress and ill health and for some, marriage breakdown.

Together, we can change this.

Based on what families are telling us, Contact a Family has launched the Counting the Costs Campaign

Join the campaign at www.cafamily.org.uk/takeaction
About the survey
The first Counting the Costs survey was carried out in 2008 because we wanted to find out how families with disabled children across the UK were affected by the economic downturn. We have repeated this survey every two years.

About the families who filled in the survey

- A quarter have more than one disabled child
- Half say they or their partner has a disability or health condition
- 28% are lone parents
- 66% of households have someone in paid employment
- A third earn less than £15,000 per year
- 68% have no pension
- Half rent or live in social housing.

Chantal & Harry
Chantal lives in Suffolk. Her son Harry is twelve years old. Harry has severe brain damage, no immunity and very complex epilepsy which means he has up to 12 seizures a day.
**SURVEY RESULTS**

**Going without**

83% of families with disabled children say they are going without

"I go without food on a daily basis. I make a £30 shop last two weeks. If there is no money left for electricity then there’s no electricity."

In winter having little or no heating makes Yasmin’s muscle spasms worse, which is extremely painful for her.

**The number of families going without food and heating has doubled:**

31% going without food

16.5% 2012

14% 2010

33% going without heating

21.5% 2012

16% 2008

And a third of those going without food and heating are doing so more than once a month.
"I haven't worn makeup in years. I only get clothes for work if something falls apart, including shoes. I feel ashamed."

"It feels like I'm constantly robbing Peter to pay Paul to pay off immediate bills."

"Cole has a lot of hospital appointments. Petrol costs, together with hospital parking are a nightmare for me."

"Not being able to get out because we simply can't afford it definitely exacerbates Katie's condition."

**GOING WITHOUT EVERYDAY ESSENTIALS**

- **DAYS OUT OR LEISURE TIME**: 84%
- **CLOTHES**: 65%
- **CAR/FUEL**: 40%
- **SPECIALIST EQUIPMENT, THERAPIES AND HOSPITAL VISITS**: 36%

**THE IMPACT OF GOING WITHOUT**

- **22%**: Say their child's health has worsened
- **13%**: Say their marriage or relationship has broken down
- **49%**: Say they have suffered ill health as a result
- **56%**: Say they have argued with their partner or children

"Going without everyday essentials day by day is..."
Karen Jones from Flint in Wales is a full time carer to her son, Aaron, who is ten years old and has severe ADHD.

One of the side effects of Aaron's medication is extreme weight-loss, which means keeping him warm when he's at home is essential. Heating the house is so expensive so I'll only put the heating on when Aaron is home in order to reduce heating costs.
In the last 12 months, half say they have fallen behind with payments – 65% on energy or utility bills

36% have taken out a loan

41% needed a loan to pay for food

50% say they needed a loan to pay off other loans/bills

36% need a loan for heating

14% have taken out five or more loans in the last year

51% threatened with court action for non-payment of bills

The majority of these have been for council tax bills and 38% for energy or utility bills

“We’re £2,000 in debt and I have taken out over 10 loans - some from loan sharks - in order to pay for essentials and to pay off other loans.”
“I have just had to sell loads of stuff in the house to get the money needed for essential winter coats for the boys. I have taken out about five loans just so I can pay for essentials - general living expenses - nothing special.”

No one ever thinks they will have to visit a food bank but you just never know.

“Friends and family tell me I must look after myself so I can look after the girls but I’m struggling to keep my head above water some months.”

“Trying to keep my head above water financially affects the whole family. I have separated from the boys’ father and have been diagnosed with depression.”

TYPES OF LOAN

- Bank Loan: 38%
- Pay Day Loan: 29%
- DWP Budgeting Loan: 22%
- Family/Friends: 45%

IMPACT OF GETTING INTO DEBT AND FALLING BEHIND WITH PAYMENTS

- 64% say they have suffered ill health as a result
- 7% have had to use a food bank
- 35% have been forced to sell or pawn something
- 93% say they feel anxious and stressed
**Extra costs**

It costs three times more to raise a disabled child*

More than a quarter of families in the survey have £300 or more extra costs relating to their child’s disability or health condition every month.

Families with disabled children have to buy things other families don’t – special food, clothing or equipment, and adapting their car or home. They also have to use and replace household goods more often.

**THE TOP 3 EXTRA COSTS**

1. Higher heating and utility bills
2. Additional transport and childcare costs
3. More frequent washing and replacing household goods, clothes, toys.

> Cole goes through a lot of bedding and clothes which he chews.

“I suffer from chronic depression and care for my ill mum too. Even if I could go back to work it would be financially impossible to find affordable and appropriate childcare for Aaron. It just doesn’t exist.”

**EXTRA BARRIERS TO WORK**

88% HAVE CARING RESPONSIBILITIES THAT MEAN THEY ARE UNABLE TO WORK AS MUCH AS THEY WOULD LIKE

72% ARE CUTTING BACK ON WORK OR GIVING UP ON CAREERS BECAUSE OF CHILDCREARE PROBLEMS

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*Joseph Rowntree Foundation 1998*
In 2008, at the start of the economic downturn almost half (47%) of families with disabled children envisaged their financial situation worsening in the next 12 months. In 2014, this figure has risen to nearly two thirds (60%). They feel they are facing an increasingly precarious financial future.

“Rachael gets Disability Living Allowance but I am very worried about what will happen when she turns 16 and this is replaced by Personal Independence Payment.”

“A lot more should be done to enable carers to work, like access to suitable childcare.”
Ellen & Cole
Ellen is from Belfast. Her son Cole is six years old and has global developmental delay, low muscle tone, epilepsy and cannot speak.

And a huge thank you to everyone who completed the Counting the Costs 2014 survey.
Contact a Family is calling on all energy companies to

1. Introduce a fixed monthly discount on all energy tariffs for households with a disabled child
2. Include disabled children in their eligibility criteria for the Warm Home Discount Scheme
3. Help set up a network of consumer champions to support families with disabled children who struggle to switch to more economical tariffs.

Contact a Family is calling on the UK Government to

1. Increase the Carer’s Allowance earnings threshold in line with any future increases in the national minimum wage, and work towards paying Carer’s Allowance to those earning up to £10,000 a year (the rate everyone starts paying income tax)
2. Increase help towards childcare costs for disabled children via tax credits, the tax-free scheme and Universal Credit, so they do not lose out by having higher childcare costs
3. Widen the criteria for the higher child disability element in Universal Credit to include children on the middle rate of DLA care component and those on the high rate for mobility.
Stop disabled children going without the basics

TAKE ACTION
Join the campaign at
www.cafamily.org.uk/takeaction

DONATE
£5 will help us give two families life-changing advice
www.cafamily.org.uk/donate

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0808 808 3555

Whatever the condition, whenever you need us, wherever you live.