

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

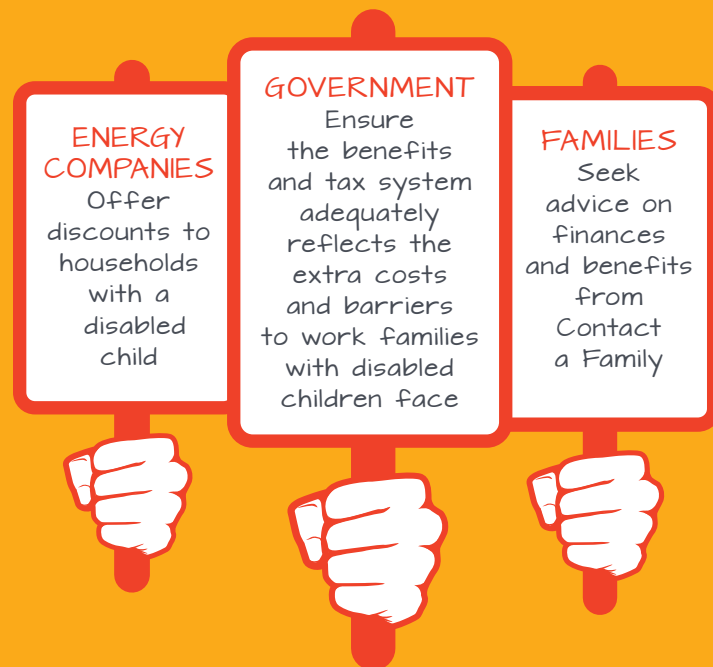
Some are going without food and heating more than once a month. Some children are even going without specialist equipment, therapies and hospital appointments.

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.

Meet the families behind the survey



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



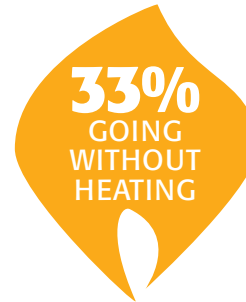
83%

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:



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. ”

GOING WITHOUT EVERYDAY ESSENTIALS



DAYS OUT OR LEISURE TIME
84%



CLOTHES
65%



CAR/FUEL
40%



SPECIALIST EQUIPMENT, THERAPIES AND HOSPITAL VISITS
36%

“ 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. ”

THE IMPACT OF GOING WITHOUT



22% SAY THEIR CHILD'S HEALTH HAS WORSENERD



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



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

Meet the families behind the survey



Karen & Aaron

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.”

Debt



In the last 12 months, half say they have fallen behind with payments – 65% on energy or utility bills



14%
HAVE TAKEN OUT
FIVE OR MORE LOANS
IN THE LAST YEAR

“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.”



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



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

“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.”

TYPES OF LOAN



BANK LOAN
38%



PAY DAY LOAN
29%



DWP BUDGETING LOAN
22%



FAMILY/FRIENDS LOAN
45%

“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.”

IMPACT OF GETTING INTO DEBT AND FALLING BEHIND WITH PAYMENTS



64%
SAY THEY HAVE SUFFERED ILL HEALTH AS A RESULT



93%
SAY THEY FEEL ANXIOUS AND STRESSED

35%
HAVE BEEN FORCED TO SELL OR PAWN SOMETHING



“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.”

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.

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

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.

“ 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 CHILDCARE PROBLEMS

Benefit changes

33%

SAY THEY ARE WORSE OFF AS A RESULT OF BENEFIT CHANGES



46%

OF WHOM ARE WORSE OFF BY £30 PER WEEK – OR £1,560 PER YEAR

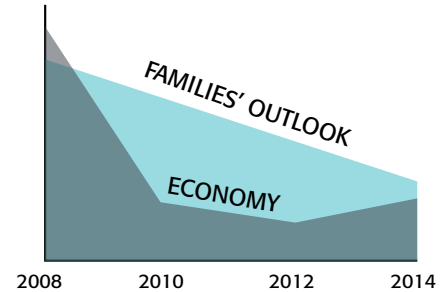


61%

SAY THEY ARE CONFUSED ABOUT HOW FUTURE BENEFIT CHANGES WILL AFFECT THEM

“ 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. ”

LOOKING AHEAD



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.

“ A lot more should be done to enable carers to work, like access to suitable childcare. ”

Meet the families behind the survey



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.

WE'D LIKE TO THANK ALL THE FAMILIES QUOTED IN THIS BOOKLET

Kirsty from South Lanarkshire. Kirsty has four children. Her two boys aged 14 and 15 have autism.

Claire from Sheffield. Yasmin is eight years old and has a motor neurone condition similar to cerebral palsy. Yasmin also has a twin sister.

Laura from Suffolk. Laura's son Ellis is six years old and has Asperger syndrome. Ellis also has a 13 year old brother.

Marina from Rochdale. Marina cares for her partner who is disabled. Her oldest son Jordan is 14 and was diagnosed with the extremely rare Dandy-Walker syndrome last year.

Melissa from Wigan. Melissa's daughter is 14 years old and has autism.

Marie from Yorkshire. Marie's daughter Katie is 15 and has autism and is profoundly deaf. She also has an 18 year old son who has autism and is profoundly deaf, who lives in full time residential care.

Lesley from London. Lesley's daughter Kirsten is 17 and has Asperger syndrome, Tourette syndrome, depression, dysthymia and ADHD.

Lisa from London. Lisa's son Joseph is aged 4 and has autism.

Cary from Plymouth. Cary's son Rohan is 17 years old and has Asperger syndrome.

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

CALL FOR ADVICE

0808 808 3555



contact a family
for families with disabled children

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

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