

COUNTING THE COSTS

Research into the finances of more than 2,700 families across the UK in 2018



contact *For families with disabled children*

EXECUTIVE SUMMARY

It is 10 years since we first asked families with disabled children about their finances. During that time disability and care costs have gone up while financial support offered through the social security system has dropped away. At the same time the system of local support for disabled children such as short breaks (respite) and therapies has been hollowed out, creating a perfect storm.

The survey findings presented in this report bring to life the consequences of all this for some of the most disabled children and their families in this country. It is truly distressing to hear sick and disabled children are going without essential therapies and equipment and are unable to make vital visits to the GP and hospital.

These are not luxuries, they are essential to keeping disabled children well and able to do everyday activities that others take for granted like eat, talk, leave the house and go to school. Sadly, the findings also suggest that this Christmas some disabled children will go without presents and treats.

That's why we are urging national and local government, alongside employers to act now in a concerted effort to give disabled children and their families the help that they deserve and have a right to.

LIFELINE APPEAL

As a charity, Contact provides a lifeline for families going without essentials. We help families navigate a system of financial support that many describe as a minefield. We unlock the system for families, helping them take back control over their lives.

In the last year alone, our Family Finances Helpline, the only specialist independent helpline of its kind, has secured an extra £2 million in financial support, that's £5,200 per year per family. That's money they didn't know they were entitled to until they called us. Looking ahead, we expect calls to our Family Finances Helpline to rocket as more and more families need advice on Universal Credit.

Families have told us how important the Family Finances Helpline is to them. Like Jenny, who said:

"Before calling the Family Finances helpline, we weren't able to do anything, we couldn't even buy things like school shoes... Now thanks to Contact we're able to pay bills, clear debt, eat better, afford school uniform and shoes for the children."

Sadly, our Family Finances Helpline is under threat.

The funding for the helpline will run out in just six months' time. We face the very real possibility of closing this lifeline. Unless we can raise the money to keep it open.

Please donate to our Lifeline Appeal today and help save our Family Finances Helpline: www.contact.org.uk/lifeline

For every £10 you give to our Lifeline Appeal, Contact can secure £130 into the pockets of families with disabled children.

Of course, raising disabled children is about more than money, but for families going without the essentials, have the money to get to GP and hospital appointments, buy specialist equipment, keep the heating on – it helps take the edge off.

KEY FINDINGS

EXTRA COSTS

33% of families have extra disability and care related costs of £300+ per month

This means it costs these families £64,800 to raise their disabled child from birth to 18 (up 6% since 2014).

10% of families have extra disability related costs of £500-£1000+ per month

This means it costs these families £110,000 to raise their disabled child from birth to 18 (up 2% since 2014)

GOING WITHOUT

40% of disabled children are going without birthday and Christmas presents

26% of disabled children are going without essential therapies (up 8% since 2014)

19% of disabled children are going without specialist equipment or adaptations

This is leading to the increased ill health of the country's most vulnerable children and their parent carers:

26% of parents said their child's condition has worsened due to going without basics (up 4% since 2014)

60% of parents say going without it has made them unwell (up 11% since 2014).

DEBT

Of those who have taken out a loan:

33% have taken out a loan to pay for food (compared to only 4% a decade ago)

28% have taken out a loan to pay for heating (compared to only 6% a decade ago)

FINANCIAL SUPPORT & BENEFIT CHANGES

56% of respondents say the disability benefits they receive only partly cover the extra costs linked to their child's disability or health condition

25% say they don't cover them at all

19% say they cover the extra costs

36% said that changes to the benefits system in the past 2 years has left their family worse off (up 3% since 2014)

"It's not us parents going without that's awful, it's our children. Especially the ones with extra needs. My son has been through so much, when he asks for things such as holidays or days out and we have to tell him no, that breaks our hearts."

Parent carer

ABOUT THE RESEARCH

From April to June 2018 we ran an online survey of families with disabled children across the UK asking them about their financial situation. It was completed by 2,772 families.

The first Counting the Costs survey was carried out in 2008 because we wanted to find out how families with disabled children were affected by the economic downturn.

Since then austerity, changes to the social security system and cuts to local services have all had an impact on the lives of the families we support.

This is the fifth Counting the Costs survey in a decade and we have repeated questions so that we can compare the situation now to a decade ago.

Contact would like to thank all the parent carers who completed our survey and shared their personal experiences with us.

Throughout the report we share some of the comments left by parent carers. In many cases these are distressing.

"It is a constant pressure. As my son's health deteriorates I worry about needing time off work as I can't afford to do this. Bills need to be paid."

Parent carer

ABOUT THE FAMILIES WHO RESPONDED

57% say they or their partner have a disability or health condition

31% are lone parents

69% of households have someone in paid employment

87% say they or their partner cannot work as much as they would like due to caring responsibilities

86% have at least one child on the care component of DLA or daily living component of PIP at the middle or highest rate, and

23% have multiple children receiving these benefits

"Our house is tiny and my son needs room for his physio, but we can't move due to bedroom tax. We're very fearful of Universal Credit particularly because the little money we earn is from self-employment."

Parent carer

EXTRA COSTS

33% have extra costs of £300+ per month for their disabled child (up 6% since 2014) or £64,800 from birth to aged 18.

10% have extra costs of £500+ each month for their disabled child (up 2% since 2014) or £108,000 from birth to aged 18.

46% of families say the biggest extra costs they face are heating, utility bills and transport.

This is because many children have conditions which require the heating to be on round the clock and the washing machine to be in use more frequently. The challenges of using public transport for some disabled children mean many families rely on expensive taxis.

Other big expenses include replacing damaged items and specialist food, clothing, toys; therapies; specialist equipment; and care costs such as respite care.

HELP TOWARDS EXTRA COSTS

Disability benefits are there to cover the extra costs, but our research shows that they are insufficient and many are missing out on vital help.

56% say disability benefits only partly cover their extra costs

25% say they don't cover them at all

19% say they cover their extra costs

IMPACT OF EXTRA COSTS

For all families (2,772 respondents):

26% are going without therapies

19% are going without specialist equipment or adaptations

13% are going without hospital or doctor appointments

60% say going without has made them unwell (up 11% since 2014)

26% say going without has made their child's condition worse (up 4% since 2014)

For those families who have extra costs of £500 or more each month (295 respondents):

41% are going without therapies

34% are going without specialist equipment or adaptations

21% are going without hospital or doctor appointments

70% say going without has made them unwell

42% say going without makes their child's condition worse.

"I have never felt so low and inadequate when I can't give my child what she needs and deserves."

Parent carer

GOING WITHOUT

80% of families with disabled children have gone without in the last year

In 2018 the main things that families are going without are:

80% holidays

72% sporting, creative and leisure activities

67% clothes

In 2008:

64% went without holidays

48% leisure

61% days out

43% clothes

Basics that families are going without:

24% are going without food (up 10% since 2008)

20% are going without heating (up 4% since 2008)

40% are going without birthday and Christmas presents.

IMPACT OF GOING WITHOUT

89% say going without makes them stressed and anxious

60% say they suffer ill health as a result (up 11% since 2014)

26% say their child's health has worsened as a result (up 4% since 2014)

15% say their marriage or relationship has broken down as a result

"We live as frugally as possible. I am not materialistic and wouldn't want a materialistic lifestyle but it is hard to see parents of non-disabled children being able to juggle a job and go on holidays and do things together as a family."

Parent carer

"I've not had any new clothes for years and neither has my partner. I'm basically a single parent because I hardly see my partner because he's always at work."

Parent carer

DEBT

35% have taken out a loan in the past year (up 9% since 2008)

43% of those had taken out one loan, 7% had taken out five or more loans and 3% had taken out 10 or more loans in the last year.

48% needed a loan to pay off other loans and bills

45% for car/car repairs/petrol

33% for food

28% for heating.

This compares to 2008 when just 4% took out a loan to pay for food and 6% for heating

TYPES OF LOAN

49% bank loan

46% family and friends

21% payday loan

18% DWP budgeting loan

4% loan shark

IMPACT OF DEBT

48% say it has caused arguments with their partner or children

5% have had to use a food bank

MISSED PAYMENTS

41% have fallen behind on payments in the past year

46% have been threatened with court action for missing payments in the past year.

“There was no other way I could afford the items. Years ago I could have saved for the items or would have had the money spare in the bank, but since having a disabled child I don’t have savings.”

Parent carer

“Our family was almost evicted from our home due to owing rent. Luckily family helped out, but it was at final stages of eviction before help came”

Parent carer

FINANCIAL SUPPORT & BENEFIT CHANGES

When asked about benefit changes over the last two years, families surveyed said:

70% are worried or very worried by the replacement of DLA with PIP for 16-24 year olds (up 7% since 2014)

68% are worried or very worried by the introduction of Universal Credit (up 16% since 2014)

36% said that changes to benefits in the past 2 years had left their family worse off (up 3% from 2014)

34% said they were unaffected by changes

27% didn't know if they were better or worse off because the changes confused them

Of those that are worse off:

37% are worse off by £30 per week or more due to benefit changes in the past 2 years.

The benefit cuts that families have been affected by include:

28% have experienced a reduction in help with council tax because local scheme replaced council tax benefit

24% unable to access one-off grants since Community Care Grants were scrapped

20% affected by housing benefit size rules, 'bedroom tax'

20% experienced a reduction in benefits due to DLA being replaced with PIP.

IMPACT OF BENEFIT CHANGES

85% say it made them stressed and anxious

52% say they have suffered ill health as a result

41% say it has caused arguments with their partner or children

"I am extremely worried about how me and my children will survive in this current environment. I feel that we have been sacrificed and scapegoated to pay for the financial crash. There is no one to fight on our behalf. The future is hopeless."

Parent carer

"The Government seems to want to make it a 'hostile environment' for anyone on benefits. I gave birth to a wonderful girl, she happens to have very complex needs and I can't work. Why is this government making me feel worthless and unvalued and making our lives so hard? I am frightened for our futures."

Parent carer

UNIVERSAL CREDIT & THE FUTURE

72% say they are worse off under Universal Credit

Of those who are worse off:

46% say it is because it is harder to manage financially with monthly payments,

43% say it is because payments are lower but they do not know why

39% say payments are lower because of cuts to the disability addition for their child

THE FUTURE

64% expect their financial situation to worsen in the next 2 years (up 17% since 2008)

30% expect it to stay the same

6% expect it to improve

“The new Universal Credit system is means-tested so any savings are taken into account. This seems very unfair when savings are for emergencies, like being unable to work if your child has to go into hospital or for equipment etc. We should be allowed a savings cushion so we don't have to take a loan out for emergency costs.”

Parent carer

SUPPORT OUR UNIVERSAL CREDIT CAMPAIGN

Contact is campaigning to stop the £175 million cut to child disability payments under Universal Credit.

More than 100,000 families with disabled children will be worse off by more than £1,750 per year as a result of the 50% cut to the child disability payment under Universal Credit.

As this research shows, families with disabled children who'll be affected in this way are already going without the essentials like food, heating and therapies. A cut of more than £1,750 a year is likely to result in increased debt, stress and ill health.

Please join our campaign network and help us stop the cut of £175 million to child disability payment under Universal Credit. Join us at www.contact.org.uk/campaigns

For more information about how Universal Credit will affect families with disabled children, please read our Universal Credit briefing at www.contact.org.uk

If you have been affected by Universal Credit and want to help us campaign please email una.summerson@contact.org.uk or call our helpline on **0808 808 3555**.

“Benefits should be there to help people, not make us feel like scroungers and thieves. We are missing quality time with our terminally ill child, all because of money.”

Parent carer

RECOMMENDATIONS

In response to the findings of our Counting the Costs survey 2018, Contact is calling on:

- 1 THE GOVERNMENT TO INCREASE SUPPORT TOWARDS DISABLED CHILDREN'S EXTRA COSTS** by uplifting rates of DLA, stopping cuts to child disability payments under Universal Credit and investing in a campaign to increase take up of child disability benefits.
- 2 THE GOVERNMENT TO PLUG THE GAP IN FUNDING FOR DISABLED CHILDREN'S SERVICES** by setting up a disabled children's fund as recommended by the Disabled Children's Partnership. This would increase free access to therapies and special equipment, so that families do not have to fund it themselves.
- 3 EMPLOYERS TO OFFER GENUINE FLEXIBLE WORKING ARRANGEMENTS** to parent carers such as working from home options and time off for a child's health appointments
- 4 YOU TO PLEASE DONATE TO OUR LIFELINE APPEAL.** For every £10 you give, we can secure £130 in the pockets of families with disabled children through our life changing Family Finances Helpline.
Please donate here:
www.contact.org.uk/lifeline

"My daughter has a life threatening condition and we want to make every day count. She is coeliac and has allergies and when she was diagnosed the food bill increased by £40 each week. Consequently I'm stressed when doing the weekly shop and sickened by the cost of specialist food. She needs physio every week but gets a maximum 10 hours a year on the NHS. So we fundraise for her therapy, which takes time and is hugely costly to our mental health. But prior to us doing this she had severe scoliosis, no head control, no use of arms, legs locked together making nappy changing impossible. Now she has full head control and use of both arms."

Parent carer



We are Contact,
the charity for
families with
disabled children.

We support
families, bring
families together
and help families
take action
for others.



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