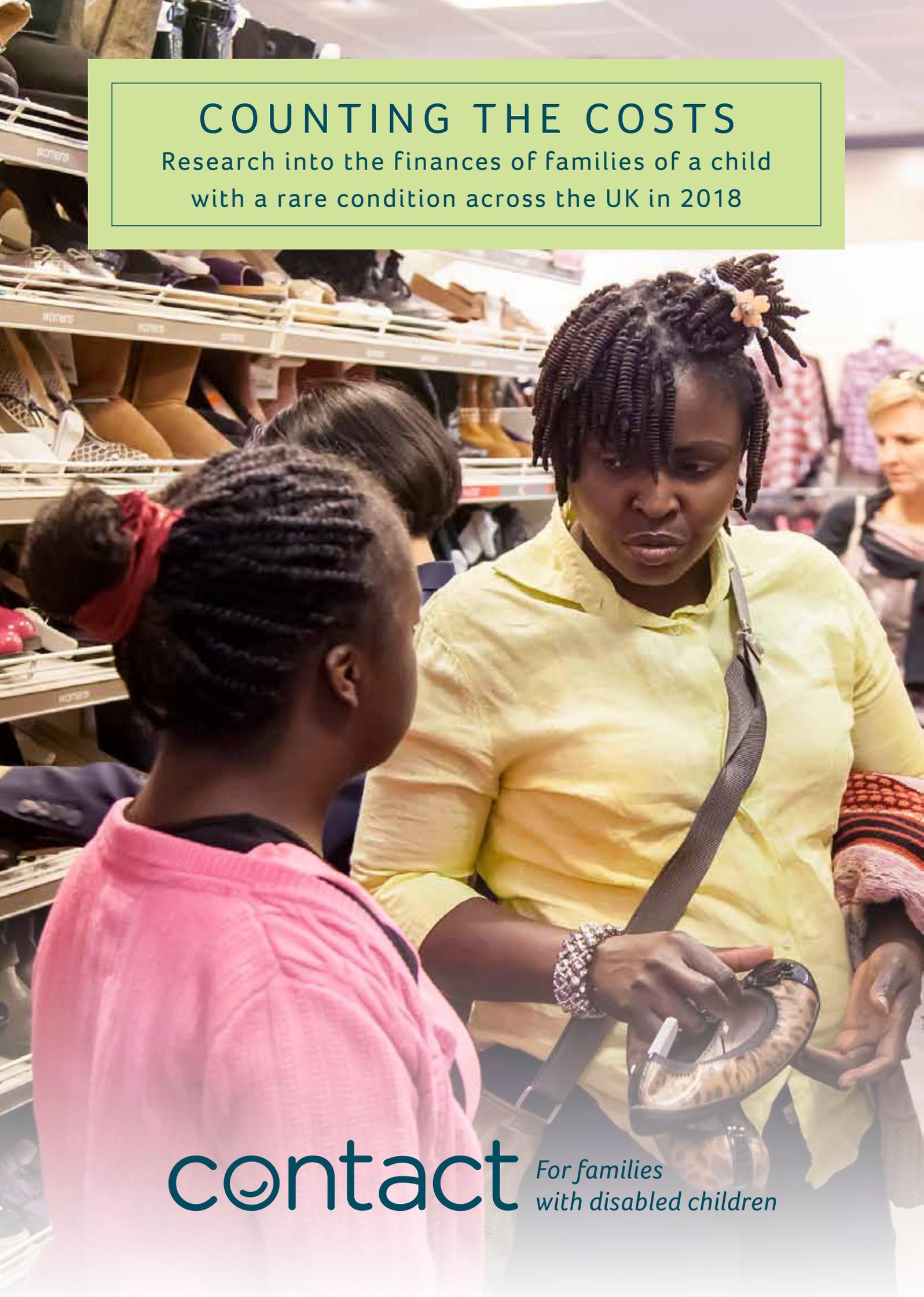


COUNTING THE COSTS

Research into the finances of families of a child with a rare condition across the UK in 2018

A photograph of two women in a retail store. The woman in the foreground, wearing a yellow shirt, is looking down at a pair of shoes she is holding. She has her hair styled in braids with a small orange flower. The woman in the background, wearing a pink shirt, is looking towards the woman in yellow. The store shelves are filled with various items, including shoes and clothing.

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) has been hollowed out, creating a perfect storm.

All this before the true impact of Universal Credit hits many families with disabled children.

The survey findings presented in this report bring to life the consequences of all this for children with rare conditions and their families. It is truly distressing to hear children with rare conditions 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.

That's why we are urging the government and employers to act now in a concerted effort to give children with rare conditions and their families the financial and practical support they deserve and have a right to.

OUR SERVICES ARE A LIFELINE – WE NEED YOUR HELP

The findings also show why our vital services are needed more than ever.

As a charity, we provide a lifeline to families of children with rare conditions. Helping them navigate the system of support that many describe as a minefield. We can unlock the system for families, helping them take back control over their lives.

In the last year alone, our Family Finances Helpline secured an extra £2 million directly into the pockets of families with disabled children, including many with rare conditions. That's £5200 per year per family.

But as a charity, we can't keep our services running without donations. If you can please support our essential work.

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

Natasha called our Family Finances Helpline. She said, "this service has changed my life, I couldn't ever be without it. I had no idea one simple phone call could do so much for me and my family and make such a difference – thank you."

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. Of those responses 462 (17%) said their child has a rare condition.

Our 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.

We are also extremely grateful to BioMarin for funding this research.

ABOUT THE FAMILIES WHO RESPONDED

26% are lone parents (5% lower than the national figure)

70% of households have someone in paid employment

89% say they or their partner cannot work as much as they would like due to caring responsibilities

"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

"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

"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

KEY FINDINGS

EXTRA COSTS

35% of families of children with a rare condition have extra disability and care-related costs of £300+ per month

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

57% say disability benefits only partly cover the extra disability costs they incur

GOING WITHOUT

80% of families of children with a rare condition say they have gone without something in the last year.

28% are going without essential therapies (compared to 26% overall)

13% are going without hospital or doctor appointments

25% of disabled children are going without specialist equipment or adaptations (compared to 19% overall)

40% are going without birthday and Christmas presents

26% are going without food (compared to 24% overall)

24% are going without heating (compared to 20% overall)

IMPACT OF GOING WITHOUT

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

20% of parents of children with a rare condition said their child's condition has worsened due to going without basics (compared to 26% overall)

63% of parents say going without it has made them unwell (compared to 60% overall)

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

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

Of families of a child with a rare condition who have taken out a loan:

37% have taken out a loan to pay for food (compared to 26% overall)

63% say it has made them unwell (60% have taken out a loan to pay for heating (compared to 60% overall))

“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

“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

BENEFIT CHANGES & THE FUTURE

35% of families of a child with a rare condition say they’re worse off due to benefit changes in the past 2 years (compared to 36% overall) and only 2% say they’re better off (same as overall)

65% are worried or very worried by replacement of DLA with PIP for 16-64 year olds, and 66% are worried or very worried by Universal Credit (compared to 70% and 68% respectively overall)

67% see their financial situation getting worse in the next 2 years (compared to 64% overall)

“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

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

"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



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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