

COUNTING THE COSTS

Research into the finances of 110 families
from Wales 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 the UK and Welsh governments, 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.

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. 110 (4%) of the respondents were from Wales.

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.

ABOUT THE FAMILIES IN WALES WHO RESPONDED

31% are lone parents

62% of households have someone in paid employment (lowest level of UK nations)

88% say they or their partner cannot work as much as they would like due to caring responsibilities

"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

"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

EXTRA COSTS

24% almost a quarter of families in Wales have extra costs of £300+ per month for their disabled child (down 6% since 2014) or £64,800 from birth to aged 18

8% of families in Wales have extra costs of £500–£1,000 each month for their disabled child (down 2% since 2014) or £110,000 from birth to aged 18

HELP TOWARDS EXTRA COSTS

Disability benefits are there to cover the extra costs, but our research shows that they are insufficient.

18% only of respondents in Wales say the disability benefits they receive cover the extra costs linked to their child's disability or health condition

64% say they partly cover the costs

17% say they don't cover them

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

Parent carer

BENEFIT CHANGES

36% of families in Wales said that changes to benefits in the past two years had left their family worse off (up 6% since 2014)

"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

"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

GOING WITHOUT

81% of families in Wales with disabled children have gone without something in the last year

In 2018 families are going without essential items such as:

24% are going without therapies (up 8% since 2014)

23% are going without hospital or doctor appointments

17% are going without specialist equipment and adaptations (down 4% since 2014)

They are also going without the basics:

45% are going without Christmas or birthday presents

35% are going without heating (down 3% since 2014)

27% are going without food (down 3% since 2014)

IMPACT OF GOING WITHOUT

65% say they suffer ill health as a result of going without (up 11% since 2014)

20% say their child's health has worsened as a result of going without (up 4% since 2014)

DEBT

40% have taken out a loan in the past year (up 9% since 2008)

"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

RECOMMENDATIONS

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

- 1 THE UK 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 WELSH GOVERNMENT, HEALTH SERVICE AND WELSH LOCAL AUTHORITIES TO PLUG THE GAP IN FUNDING FOR DISABLED CHILDREN'S SERVICES** 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

"Dylan is very bright and is at college doing Computer Science, Chemistry and Biology 'A' levels. But he is very socially isolated as he finds it hard to make friends due to his condition and I would like to get him support with that, because it can be very hard as a parent. I've tried to get support from CAMHS for Dylan, but they are so stretched and only see the most extreme cases that they won't entertain seeing him. Things are a struggle at times. We have seen a drop in our financial support over the last two years. Our tax credits were cut and when Dylan moved onto Personal Independence Payment, he was granted standard care. He had been on high rate care Disability Living Allowance, so this was a significant reduction in the help he receives. I'm in the process of appealing the decision. I'd like to go back to work but if I work 16 hours a week at minimum wage I would lose my Carer's Allowance, even though I'll be providing the same level of care. I would also lose tax credits so would be worse off and would struggle to pay the bills. The system doesn't help families like ours."

Mandy from Wrexham, mum to Dylan aged 17 who has autism



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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