

**contact** a family  
for families with disabled children



# Counting the Costs 2012

The financial reality for families with disabled children across the UK

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition.

## About the survey

*Counting the Costs 2012*, is a report based on an online survey carried out between 20 February and 11 March 2012. It was made up of open and closed questions. It is a repeat of a survey carried out by Contact a Family in 2008 and 2010, and some of the same questions have been used to enable comparison. However, additional questions were added to the 2012 survey on changes to the benefits systems in light of welfare reforms. We also wanted to find out how families with disabled children are feeling about claiming benefits. This was prompted by negative stories in the press about disabled benefit claimants.

A qualitative, thematic analysis approach was used to understand and analyse the open ended responses. This report provides a summary of both the quantitative and qualitative results.

## About the respondents

Our *Counting the Costs 2012* survey was completed by 2,312 parent carers<sup>2</sup> across all four nations of the UK.

- 496 have a disabled child aged 0-5
- 1532 have a disabled child aged 6-15
- 348 have a disabled young person aged 16-19
- 158 have a disabled adult aged 20+

22% of respondents care for more than one disabled child/young person, with over 100 respondents caring for three or more disabled children.

76% are in a couple, 24% are lone parents.

Contact a Family would like to thank all the parent carers who completed our survey and shared their personal, often distressing experiences with us. We received the highest ever response to a Contact a Family survey.

<sup>1</sup> This includes mothers, fathers and grandparents of disabled children and young people

Alesha Dixon, pop star and Britain's Got Talent judge, is supporting Contact a Family by encouraging families with disabled children to make sure they get the help they are entitled to. Having read the results of our survey, she said:

"It's shocking that so many families with a disabled child are going without food and heating – things all of us take for granted. It's great to know that Contact a Family is there with the expertise and knowledge to help families deal with these difficulties. If you have a disabled child, please make sure you get advice by calling Contact a Family, where experts can point you in the right direction."

**Alesha Dixon**

## Summary

All families have been feeling the pinch and facing difficult decisions about managing their family budgets. Household prices are soaring across the UK – especially fuel and food costs, unemployment is high and cuts to some benefits and tax credits are affecting many families.

*Counting the Costs 2012*, in line with our findings from 2008 and 2010, shows going without essentials and getting into debt to pay for food, heating and clothes is the norm for most families with disabled children. Parent carers talk about the harsh choices they constantly have to make, the unfairness and the shame they feel when they can't afford specialist equipment and toys – essential for their children's safety, development and dignity. This is not something new created by the economic downturn, recession or austerity measures.

**“The lack of money has always been a strain; the pressure is a constant, demeaning struggle. We are trapped by circumstances and have always faced impossibly difficult decisions.”<sup>2</sup>**

In 2012, the need to reduce the budget deficit has created new pressures on vital benefits and services for families with disabled children already experiencing persistent poverty. Our findings show that some have already been affected by changes to the benefits system, which is worsening families' financial situation. For many others they are extremely distressed about having to cut back further when the cumulative impact of welfare reforms hit. They are also confused about the changes to the benefit system and as a result feel unable to plan for the future. This is adding unnecessary additional strain on them. This on top of the practical, physical and emotional challenges of caring for a disabled child not experienced by other families.

**“As if parents of disabled children don't have enough to worry about, having to choose between paying for heating or food each month is definitely not what we need on top, it's so unfair.”**

## Key Findings

Our survey of 2,312 families with disabled children across the UK shows:

### they are going without essentials

- 1 in 6 (17%) is going without food.
- More than 1 in 5 (21%) is going without heating.
- A quarter (26%) are going without specialist equipment or adaptations.
- 86% have gone without leisure and days out.

### they are getting into debt to pay for essentials

- Almost a third (29%) have taken out a loan - 39% for food and heating
  - a quarter of loans are from quick cash schemes or from loan sharks.
- 1 in 5 (21%) have been threatened with court action for failing to keep up with payments – the majority for missing utility bill payments (46%).

### they are worried about benefit changes

- Nearly 60% think that their financial situation will get worse in the next 12 months (this is up 15% from 2010) - 73% citing welfare reforms as the main reason for this.
- Families with disabled children are most worried about the replacement of Disability Living Allowance (DLA) by Personal Independence Payment (PIP) for 16-64 year olds (50%), the introduction of Universal Credit (21%) and housing benefit restriction (17%).
- Over one in ten (11%) have already been affected by benefit changes.

### they are facing stigma associated with claiming benefits

- Hard working parent carers feel branded as work-shy scroungers for claiming vital benefits for their disabled child.
- They feel an escalating climate of hostility towards those claiming disability benefits has left them feeling ashamed about getting the help they are entitled to for their child.

<sup>2</sup> Unless specified all quotes in this report are from parent carers that responded to the survey

*Counting the Costs 2012* also reveals the level of stigmatization of families with disabled children. The lack of understanding from society about the considerable extra and ongoing costs of raising a disabled child, and the invisible carer contribution to the economy<sup>3</sup> is leaving many parent carers having to justify themselves and their disabled children as being 'disabled or worthy enough' to claim benefits. Many feel recent media and government messaging has increased the level of vitriol against families with disabled children (whether they claim benefits or not).

Money worries are putting huge emotional and mental strain on parent carers, pushing some to breaking point. Contact a Family wants to make sure supporting families with disabled children is everyone's business. We urgently need combined action by government, local authorities, energy companies, employers, frontline professionals and the voluntary sector to make it better for families with

Research shows that families with disabled children are more likely to be living in poverty than other families<sup>4</sup>. It costs three times as much to raise a disabled child<sup>5</sup>. This shopping list illustrates some of the extra costs associated with caring for a disabled child.

Extra costs shopping list	
Costs for a disabled child	Costs for a non-disabled child
A month's worth of pull-up nappies and wipes for a 5 year old disabled child: £60	A month's worth of pull-up nappies and wipes for a non-disabled five year old: £0
Specially made car safety seat: £600	High back car booster seat from : £149.99
Specially measured sandals for 8 year old disabled child: £120	Sandals for a non-disabled child from a high street shoe shop: £34
Sensory wooden toy: £1,000	Wooden blocks in a wagon toy from a toy superstore: £16.99
Specially adapted bicycle for an 11 year old disabled boy: £800	Bicycle for non-disabled 11 year old from a high street store: £79
Seamless socks: £6 a pair	Pack of 5 white children's socks from a supermarket £2 for a pack of 5 (or 40p per pair)
Special 'pea pod' supportive bean bag: £385	Beanbag with cotton cover: £24.99
Touchscreen computer – essential for school work: £800	Computer: £259.99
Specialist mouse for computer: £200	Mouse for computer: £19.99
Big Keys keyboard for computer: £150	Keyboard: £39.99
<b>TOTAL:</b> <b>£4,121</b>	<b>TOTAL:</b> <b>£624.98</b> <small>Source: Collated from costs from a ranges of families with disabled children.</small>

<sup>3</sup> Care is worth £45,990 a year (based on 7 hours per day each week using the Carers UK care calculator) to the UK economy. Carers save the UK £119 billion a year [www.carersuk.org.uk](http://www.carersuk.org.uk)

<sup>4</sup> Department of Work and Pensions 2006/07. Households Below Average Income showed the risk of relative poverty for families with a disabled child but no disabled adult family member has increased from 20% to 25%, meaning disabled children are now at greater risk of living in relative poverty than non-disabled children.

<sup>5</sup> *Paying to Care: the costs of childhood disability* by Barbara Dobson and Sue Middleton

disabled children across the UK to tackle the unacceptable persistent and increasing poverty they are experiencing.

*"I am fed up with people accusing me of making my son's disability up. Some even go as far as to accuse us of having a wheelchair, not because he needs it but so I can scrounge off decent people. The negative comments and hostility have got a thousand times worse in my experience. What they don't understand is how dependent the state is on us carers not us on them."*



## Recommendations

- Contact a Family is calling on government to **make it better** by setting out how and when they intend improving incomes for all families with disabled children<sup>6</sup>, not just through work, but through improvement of benefits for carers and those they care for<sup>7</sup>.
- Contact a Family is calling on energy companies to **make it better** by joining the Warm Home Discount scheme and guaranteeing an automatic £120 payment to any child in receipt of Disability Living Allowance (DLA) next winter.
- Contact a Family is calling on local councils to **make it better** for families with disabled children by protecting them from cuts under Council Tax Benefit reform (that is, by treating families with disabled children in the same way as pensioners)
- Contact a Family is calling on all frontline professionals and the voluntary sector to **make it better** for families with disabled children by signposting them to specialist benefits and debt advice services and other sources of specialist parenting support.
- Contact a Family is calling on families with disabled children to **make it better** by claiming benefits and other entitlements. Benefits such as DLA are designed to help cover some of the additional costs of disability and are often the 'passport' to other sources of help. With all the changes happening to the current and future benefits system it's important to seek regular advice.

"Our current battle is trying to get a bicycle for our young son, a disabled 11 year old. My older son's bikes have never cost more than £50 and have generally been second hand. Getting Isaac, our disabled lad, a bike is a very different ball game. The cheapest we have found is £800 because he needs two wheels at the back, a waist cradle and harness to support him, and it needs to be a tag-along bike so my husband can pull him with his bike. So, Isaac can't have a bike, because we can't afford it. It just makes me mad that things are so much more expensive when you have a child who has disabilities. He longs for a bike and to be able to join in!"

<sup>6</sup> We define disabled children/young people as those affected by a wide variety of disabilities and multiple conditions including those with life limiting conditions, rare syndromes, behavioural and mental health problems. This may also include children with special educational needs (SEN).

<sup>7</sup> Specific recommendations regarding welfare reforms in the main sections of the report.

## Survey results

### Going without essentials

In the last 12 months, 82% of families with disabled children said they had to go without something because of a lack of money. Since 2010, more families with disabled children are going without food, clothes, specialist equipment, days out and holidays.

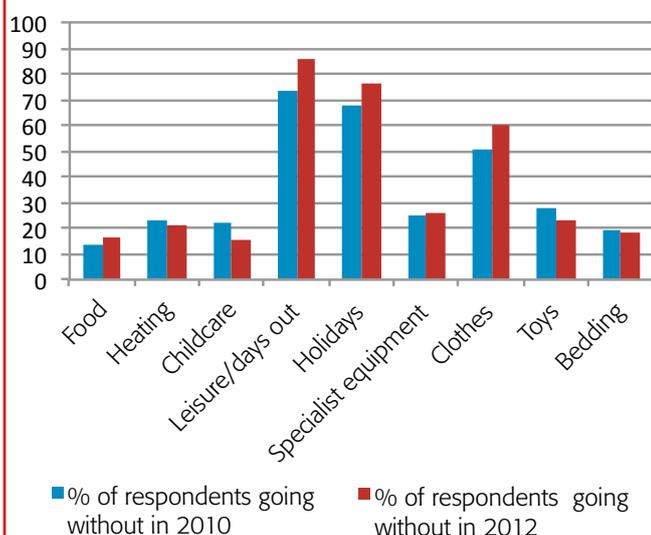
"I've done everything I can to make sure I spend the bare minimum but it is still a daily struggle to make ends meet. I've axed my weekly shop and regularly go without meals to make sure Leon has enough. He gets upset when I don't eat but I just tell him not to worry as I'm not hungry. I only put the heating on early morning and evening and at the weekends – basically when Leon is in the house. He needs specially-measured shoes which are very expensive. I've borrowed money from family to pay for food, gas and electric and I took out a credit card for Leon's school uniform and footwear, which I am now paying this off at £20 a month. I'm really worried about the future."



For those in paid employment, one in seven (14%) is going without food and one in six (17%) is going without heating. Where no one in the household works, often due to their caring responsibilities, almost a quarter (24%) is going without food and a third (32%) without heating because they cannot afford it.

"I do everything I can, but because both our disabled children need 24/7 support my wife and I just can't work. I was a teacher before. I feel ashamed that I can't buy the special pull-up nappies that give my teenagers some dignity, the council ones aren't decent. I would love to take my wife out for dinner or buy her a new dress. I'm not complaining as my children are amazing, but I do think it's unfair that we have to go without because disability means extra costs."

### What parent carers have gone without in the last 12 months



When we asked parent carers to tell us more about going without, they very commonly said they went without themselves in order to pay for things for their children. This was often cited around skipping meals and having no luxuries of any kind including things like haircuts, new clothes, toiletries, and winter coats. The lengths of going without seem to be endless and can be around big things too – going without the career they loved, downsizing housing, or going without a car. Often the fear of getting into debt, or more debt, prompted people to make choices about going without rather than going into debt. This was a prevalent finding and often how much families with disabled children went without was related to emotional stress of trying to cope.



"I go without so my children can eat and I can pay bills to keep a roof over my family's head. I sometimes use pay day loans, I try not to, but sometimes we need them to keep afloat. I feel like I am going round in circles borrowing money. I'm trying my hardest and I'm desperate to work but it is a nightmare to find part-time work to fit around Jack's caring needs."

Parent carers said they were going without clothes and using more second-hand clothes for their children. They find this extremely difficult and stressful due to the direct impact on their children's visible disadvantage. In some cases they felt it had led to bullying.

Looking ahead, the future is bleak for many families with disabled children. Some can't cope with the thought of having to cut more, as they are already on the bare minimum. Some sense that the struggle will become worse when their child turns 16. Moving into adulthood is difficult for a range of reasons. The higher costs associated with a disabled young person establishing independent living and employment for the first time and a loss of benefits and support is viewed as particularly devastating and leads to further harsh and forced choices.

"As a single mother who receives no maintenance and who has been diagnosed with fibromyalgia after a spine op and now depression, I just worry constantly about money. It feels as though, now my disabled child is 17, he is cut off from all financial help. My son has to attend a school 10 miles away and every week I worry that I can't afford the petrol as he's not eligible for a school bus."

### The emotional and mental strain of going without

We asked parent carers to tell us about the emotional impact of having to go without. The overwhelming response is of pressure, anxiety and constant worry. It is commonly linked to stretching and straining family relationships to breaking point. Marriages are suffering and this is impacting directly on their children.

Many parent carers described the impact of stress as having a sustained, negative impact on their mental health. They talk about depression, anxiety, lack of sleep, stress, guilt for not being able to provide enough and having nowhere to turn to. Parent carers expressed a sense of constantly failing with no end in sight, and an acknowledgement that the pressure of money worries was having a negative impact on parenting. Families with disabled children are performing a balancing act, with no room for manoeuvre. They are unable to plan or save for the future or emergencies.

"We are both working hard but will not be able to afford to bring our property up to modern standards, we are barely able to afford the costs of the mortgage, utilities and the food bill. We accept our situation, we take responsibility for our family but we are feeling the strain."



## Cutting back more

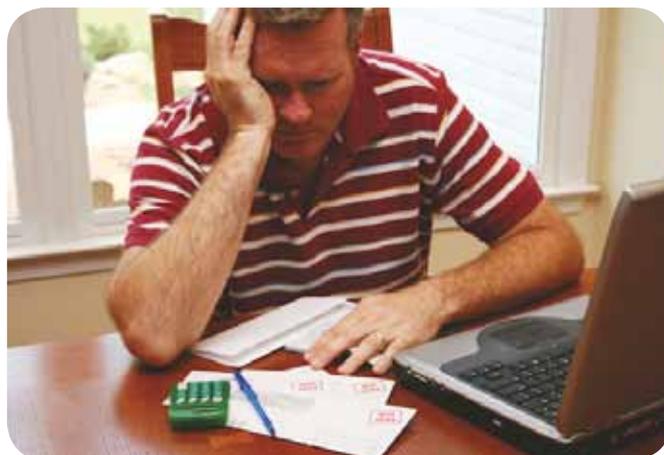
We asked families with disabled children (where no one in the household was in paid employment and did not receive high rate care DLA for their disabled child) to tell us what a cut of £26 would mean to them. We asked this because the government has proposed making cuts in additional disability payments for children of this amount. These are currently paid as part of means-tested benefits and tax credits. The cut will start to happen from October 2013 as part of the introduction of the Universal Credit<sup>8</sup>.

“As prices for everything just keep going up I have gone without things just to keep up with payments. Being a lone parent makes it hard to get financial help. It makes me angry and depressed knowing there is always a threat of more cut backs with any disability funding. You can't plan for a future as it is so uncertain.”

Recurrent themes from families with disabled children who will be affected by this proposal focused on cutting even further into a life that was already unfairly strained and based on survival, rather than living. A cut of £26 would mean they would suffer even more, as would their children.



<sup>8</sup> To date, the Government's stated policy has been that the support that many low income and out of work families with disabled children currently receive under Tax Credits and Income Support will be reduced by 50% when Universal Credit is introduced in 2013. This reduction in support will apply to all families with disabled children in receipt of the high rate mobility component of DLA, the mid and low care rates of Disability Living Allowance.



“This is a lot of money for a family with nothing. This will hurt us even more, I wish I had a choice but nothing can give, I would be happy to work but it's impossible to get anyone to understand Charlie's needs. I promise we have tried, anyway the council told us it's better I stay at home as it saves them having to provide extra support.”

Food is very often cited as being one of the things they could go without more because there was simply nothing else left to cut back on. Often, families with disabled children were already going without one or two meals a week and thought this would have to increase. Many were concerned about the implication of this, not only in terms of the impact on healthy eating for the whole family but for children with specific diets and conditions. Parents felt this would directly affect their child's behaviour and health for the worse.

Cutting back further on heating was commonly cited as a possible option. The analysis identified that this was not an easy choice for parent carers because they are at home more and need heating for reasons linked to their child's disability. Parent carers were very distressed about having to possibly cut back further on heating, as this was seen as something that is already carefully monitored and used because of high fuel costs.

Some said that the rising costs of petrol for their car was putting so much pressure on them already that the added cut would force them into selling their car, as nothing else would give in their budget. This was constantly referred to as a dire consequence, as families' isolation would increase further and their children would suffer (not able to go to school or appointments). Families without cars talked of the high cost of public transport and said they would have to stop using it and walk, or remain even more isolated.

“Walking or using public transport isn’t an option. Dillon can’t deal with public transport as it is too unpredictable, and if he gets distressed he will just stop walking. So we use a lot of petrol. Dillon is home educated so we have the heating on a lot more often. We had to take out a bank loan to get some safety equipment that social services said we needed but wouldn’t fund. This included a safety door and window restrictors, so was vital for Dillon’s safety and well being.”

Parent carers talked about cutting back on ‘small treats’, and birthday/Christmas presents, or stopping extracurricular activities for their disabled and non-disabled children. This they felt would be traumatic and would increase feelings of guilt over their children’s happiness. Cutting out extracurricular activities for children was seen as actively hindering their development.

“It constantly puts a strain on what I can and can’t buy and it’s upsetting when I always have to say no to my daughter even when she only wants a little treat! It makes life difficult when I can’t afford to pay someone to do simple repairs on the rented home I live in as the council wouldn’t help me and private landlords aren’t very co-operative.”

Often families with disabled children said the struggle to pay bills such as the rent or gas and electric would mean any cut to financial support would lead to an increase in decision-making about “which bill to pay, and which to not”. Some parents feared they would be at risk of losing their house and would have to move.

We welcome the Government’s commitment to continue to provide disability additions within the Universal Credit. However, Contact a Family is extremely concerned about the Government’s decision to halve current financial support available, to out of work families with disabled children who do not receive high rate care component of DLA. This will lead to a reduction in financial support of nearly £1,400 per year for new claimants from 2013.



**Contact a Family is calling on the government to:**

- provide at least current levels of financial support through disability additions via Universal Credit to all families with disabled children; and
- bring forward the review of the disability additions policy which Lord Freud, Minister for Welfare Reform, committed to undertake in 2015.

To help reduce the persistent fuel poverty experienced by families with disabled children across the UK, Contact a Family is calling on energy companies to join the Warm Home Discount scheme and guarantee an automatic £120 payment to any child in receipt of Disability Living Allowance (DLA) next winter.

The carer contribution is worth £45,990 a year (based on seven hours per day each week<sup>9</sup>) to the UK economy. It makes financial sense to support carers. These measures will mean families with disabled children will have enough to spend on the basics like heating, food and clothes.

**We are also calling on all frontline professionals and the voluntary sector to be proactive about signposting parent carers to specialist benefits and debt advice services and other sources of specialist parenting support.**

This will give parent carers the information and advice they need to claim benefits and other entitlements. Benefits such as DLA are designed to help cover some of the additional costs of disability and are often the passport to other sources of help, yet around a half of families with disabled children don't claim it.

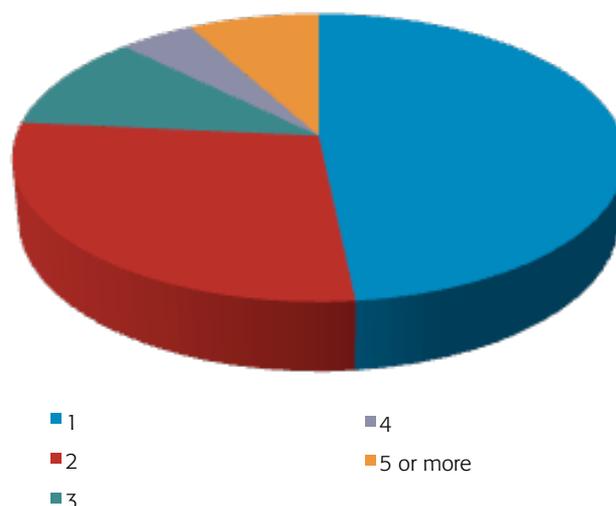
**Debt and falling behind with payments**

In the last 12 months, 29% (up 4% from 2010) of families with disabled children have taken out a loan—a quarter from sources that often incur extortionate interest rates, such as loan sharks or quick cash schemes.

“We get paid on Friday and come Tuesday we have nothing so we have taken out three pay day loans in the last 12 months and borrowed money from family. This isn't to pay for luxuries, it is for essentials like the groceries.”



**Number of loans taken out in the last 12 months**

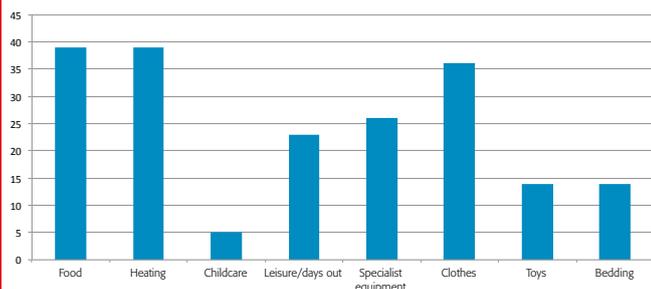


<sup>9</sup> Calculated using the Carers UK 'Care Calculator' <http://www.carersuk.org/>

'What kind of loan have you taken out?' Respondents could tick all that applied	Number	Percentage
Bank loan	339	54%
Internet/quick/pay loan	129	20%
Unlicensed moneylender (loan shark)	30	5%
Family or friends	250	40%
Other, for example, credit union, remortgage	115	23%

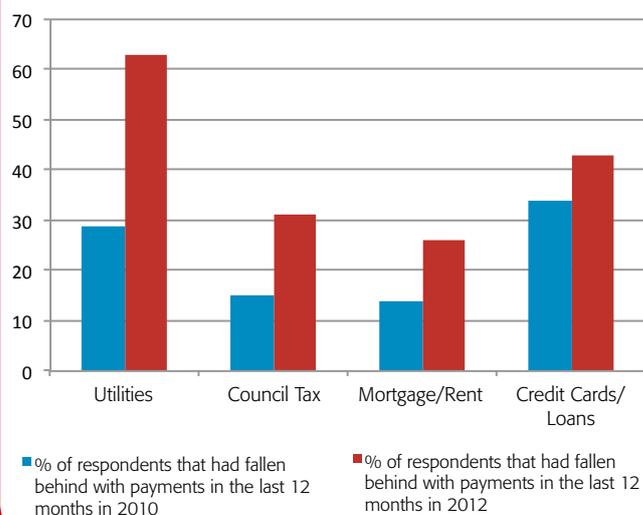
For many families with disabled children, they are taking out loans for basics not for luxuries. The majority are borrowing money to spend on heating, food and clothes. Some parent carers, (26%) are taking out loans to pay for specialist equipment and adaptations – essential for the safety and dignity of their disabled children. This could range from incontinence products and sensory toys to wheelchairs and home adaptations.

### Of those that took out a loan % spent it on:



In the last 12 months, 41% (up from 34% in 2010), of families with disabled children have fallen behind with payments. They are increasingly falling behind with payments for utilities, Council Tax, the mortgage, or rent and credit cards loans.

### Proportion of families with disabled children that have fallen behind with payments in the last 12 months



Nearly 500 families with disabled children have also been threatened with court action for failing to keep up with debt payments. Court action over utility bills arrears has increased 46% compared to 40% in 2010. In all other areas of debt action, there has seen a significant fall.

- ✓ 37% down from 65% in 2010 for Council Tax arrears
- ✓ 32% down from 38% in 2010 for credit cards/loans arrears
- ✓ 18% down from 43% in 2010 for mortgage/rent arrears.

“Before our son was born we coped fine with our debts. It was after we learnt that he had severe brain damage and required 24-hour care my husband and I had to leave work to care for him. This left us in lots of debt and puts a lot of stress on to us.”



## **The emotional pressure of debt and falling behind with payments**

We asked parent carers to tell us more about borrowing money, falling behind with payments and their debts. The comments reflect the financial strain on them which is having dramatic and negative impacts on family relationships and parental mental health. Parents talk about the impossible burden of what they owe, having to 'rob Peter to pay Paul' to pay for the basics, and the shame and guilt associated with debt.

"We are on a really tight budget and we have to keep a tight control on what is coming in and what is going out. We do live in our overdraft, the thought of having to suddenly pay them back keeps me awake at night. It's frightening and scary to live beyond your means."

Many families with disabled children are fearful of borrowing and are often confused about what they owe and their repayments. Parent carers talk about desperately wanting to avoid debt because of the stress it causes. Others say they borrow from family rather than formal institutions for fear of not being able to repay the loan.

"We go without so that we don't fall behind with bills because if we did we would NEVER be able to dig ourselves out. We are struggling to live and there's nothing we can do. My son is going to need support for his whole life."

Some foresee getting into more and more debt as inevitable. The comments also reflected a strong sense of unfairness. Families with disabled children feel trapped by circumstance due to the unavoidable higher costs of raising a disabled child and the difficulty of working and caring.

Some talked about the difficulties of getting credit or loans because Carer's Allowance is classed as unemployment by banks. For others, this was another form of discrimination and a lack of recognition for them as hard working carers.

## **Contact a Family is calling on local councils to stop families with disabled children getting into more debt and falling behind with payments by:**

- protecting them from cuts under council tax benefit reform (by treating families with disabled children in the same way as pensioners)
- disregarding DLA payments when calculating entitlement to discretionary housing payment (DHP)
- treating families with disabled children as a priority group under discretionary housing payment (DHP)
- not cutting services that provide locally available specialist benefit and debt advice services.



## Future financial worries and the impact of benefit changes

Families with disabled children are increasingly worried about their financial situation. Nearly 60% said they feared that their financial situation would worsen in the next year, this is up 15% from 2010.

“As if life isn’t stressful enough these benefit changes are an additional financial worry, it really is putting a strain on my relationship with my husband.”

When asked the two main reasons for this, the majority of families with disabled children (73%) cited welfare reforms. Other reasons included:

- 64% cited the economic climate (up from 43% in 2010)
- 60% cited the difficulty of working and being a carer (up from 52% in 2010)
- 59% cited the expenses associated with their disabled child (up from 52% in 2010)
- 58% cited changing family circumstances (up from 27% in 2010).

“I’ve lost £300 a month due to benefit changes. I can barely put food on the table and can’t meet my monthly bills for essentials. I now buy cheaper processed food but it’s not good for my son’s diet.”

The Government’s Spending Review in 2010 set out plans for fundamental reform of the welfare system, making savings of £7 billion each year by 2014-15<sup>10</sup>. Since *Counting the Costs 2010*, we have seen the announcement of a number of major reforms to the benefits and tax credits system as a result. This amounts to one of the most far-reaching overhauls of the welfare system in generations.

We asked families with disabled children to tell us about the benefits changes that have already affected them and what this had meant for family life. Lots of those who responded detailed how much they have lost, ranging from £30 per week, to £850 per month (depending on the benefits claimed and how many children respondents have). Over one in ten (11%) have been affected by benefit changes to housing benefit restriction and the scrapping of Employment and Support Allowance (ESA) in youth.

“The Welfare Reforms are already hitting us very hard in that I am unable to work because of Thomas’s needs but my husband is a relatively high earner – very slightly over the threshold for losing all Child Benefit. So I feel that we are between a rock and a hard place – a large part of our income is being taken away but we are not in a position to replace it by my working.”

As a result of this loss of income, lots of parent carers felt burdened and unsure how to cope. Common themes included being unable to buy specialist equipment for children – whether sensory, educational, or medical or struggling to pay for travel costs of getting to work or taking children to school. Some families have had to move to smaller and unsuitable accommodation. For some they are facing homelessness.

“The housing benefit cuts means I’m facing forced eviction and my 12 year old child tried to commit suicide because of this.”

The Government has confirmed that, from April 2013, there will be an extension of the principle of Local Housing Allowance (LHA) to tenants in social housing<sup>11</sup>. This already affects many families with disabled children living in private rented property. We expect the number of families with disabled children running into problems with rent arrears is likely to increase dramatically as a result.

### Contact a Family is calling on government to:

- exempt families with disabled children from the Local Housing Allowance (LHA) rule that says that two children of the same sex aged under 16, or two children of any sex aged under 10 should always expect to share a room. Disabled children can need care frequently during the night which disrupts the sleep of other children they are sharing a room with.
- apply the LHA extra room allowance for a non-family carer to disabled children as well as disabled adults; particularly those children with complex needs who may need non-family carer to support them during the night.

10 [http://www.direct.gov.uk/en/N11/Newsroom/SpendingReview/DG\\_191799](http://www.direct.gov.uk/en/N11/Newsroom/SpendingReview/DG_191799)

11 Contact a Family (2012) *The Cumulative Effect – The impact of welfare reforms on families with disabled children now and for future generations* soon to be published.



“Many families with disabled children don’t understand what changes are coming and it feels like nobody is fighting our corner anymore. People in charge seem to forget that there is a real human cost to all of these welfare and benefit changes and I find myself getting more and more angry at the impact that government policies are having on two beautiful boys.”

Because the full details of the Welfare Reform Act 2012 are currently not available but will be provided in regulations, it has not been possible for us to work out the overall impact of on different families. For example, we have been able to calculate how discreet payments with Universal Credit may affect families (for example, the disability additions, or help with childcare costs) but we are currently unable to work out what the overall entitlement for families is likely to be. This means we don’t yet know who will be better or worse off. It is clear from our survey results that this has left many parent carers worried and confused about future benefit changes – compounding the emotional and financial anxiety already experienced on a daily basis..

Families with disabled children are most worried by:

- replacement of Disability Living Allowance (DLA) by Personal Independence Payment (PIP) for 16-64 year olds (50%)
- introduction of Universal Credit (21%)
- Housing Benefit restriction (18%)

Contact a Family produces a future benefit changes guide. We urge parent carers worried about these changes to contact us for a copy and advice.

“The governments haste to rush through the reforms, any sense of decency and empathy has been erased. They have done nothing to quell the scrounger frenzy fuelled by the red tops about people with additional needs. There will be no quality of life for me and my daughter. She has such a lot to cope with being a young woman with health issues, without this added stress.”

### **Stigma and attitudes towards families with disabled children claiming benefits**

We asked parent carers to tell us about how they think others view them as a benefit claimant for their disabled child and/or themselves.

“I think others see us as people who just take. It never occurs to them that they get too. They get schools fit for their kids, playgrounds their kids can access, after school clubs so they can have successful careers. They get so much and they have no concept that they cost society more than us.”



In general, there were distinct positive and negative perceptions. Overall parent carers felt that close family and friends understood the financial implications of raising a child with a disability and were happy for the family to receive benefits. There was a repeated thread where close family and friends recognised that carers allowance should pay more in order to support the family better. However, perceptions are negative outside the close family circle.

### **Verbal discrimination**

Parent carers constantly referred to negative verbal discrimination such as scrounger, scum, lazy, work-shy, cheating the system. They are experiencing this from neighbours but also from jobcentre and local authority staff.

They felt that the negative judgments they experience are rooted in a lack of understanding of what daily life and extra costs are involved in raising disabled children. They also feel that recent media and government messages have increased the level of vitriol against families with disabled children (whether people know they claim benefits or not). In our survey parent carers described incidents of hate crime.

These factors are having direct emotional impacts on families with disabled children– they say they feel like outsiders, low in society, and second class citizens. Many feel ashamed and afraid of admitting they claim benefits. Some said they don't claim benefits because of the intense negative stigma attached.

### **Negative perceptions**

Many felt that claiming benefits for a disabled child puts them into the same cohort as being judged as those that are unwilling to work, live off the state and are dependent on welfare.

Others felt that public perception of families with disabled children is one of being well off or making money out of their child's disability. Often, families with disabled children referred to struggling along on benefits and yet were perceived as getting a lot for nothing. Some also said that their Motorability cars were frowned upon by others and seen as a perk.

*"Families are saving the state an absolute fortune, but the government is cutting back further. People are getting further and further into debt and the government doesn't understand that they are shifting the problem from one place to another, they are not getting rid of it."*



*"A few months ago I was on a bus with my son who has cerebral palsy. A woman got on and looked at Owen's wheelchair and demanded to know how much I had to bribe the NHS to get a wheelchair like that! Another time a bus driver actually told me that he wished we were in Nazi Germany where people like my son wouldn't exist. Extreme incidents like this are fortunately rare but I am hearing more and more similar stories from friends with disabled children. Things are definitely getting worse. There has been a lot more targeting around the whole idea that anyone who claiming disability benefits is essentially lying. It feels like more people than ever now believe that there are millions of people out there claiming disability benefits fraudulently. People now feel they have the right to question you to see if you are one of the 'liars' the media constantly talk about. My son isn't stupid. He knows what people are saying and is starting to understand that he is different and asks me why people behave towards him in the way they do."*



### ***Having to justify themselves and being 'disabled enough'***

Parents of children with autism or learning disabilities that are less visible disabilities referred to being particularly misunderstood by society. They felt that unless a child uses a wheelchair or has a physical disability, they not only experienced difficulties in claiming benefits, but are judged negatively for claiming and capitalising on their child's diagnosis. Many families with disabled children want others to understand, to "walk in my shoes for a few days" and see what life is really like, and what it really costs.

Some spoke about how they often have to justify themselves in society for claiming benefits. This they felt is directly related to the perceptions that benefits claimants are seen as scrounging off society.

**"All this talk being dependency on welfare is really upsetting and hurtful to those caring for disabled children. But it's the wrong way round; it's the state that is dependent on us carers."**

A lot of families with disabled children talk about how Carer's Allowance is highly misunderstood by others, and that people do not understand that they are unable to work due to caring responsibilities, and that it is not a case of not wanting to work.

### **Going without days out means more isolation**

- 86% of families with disabled children are going without leisure and days out. This is up from 75% in 2010.
- 77% are going without holidays.

Families with disabled children are often more isolated than other families and a lack of money is one of the main causes<sup>12</sup>. There has been a dramatic jump of 38% since we first conducted *Counting the Cost*, in 2008, of families with disabled children going without days out and leisure activities.

**"I hate having to live in a permanent state of stress worrying if I'm going to get through the weeks. My son is also becoming more and more isolated as I don't have the cash to take him out to experience the world around him."**

Leisure and days out for a family with a disabled child are often basic activities, such as swimming or going to the local park that other families would take for granted.

Disabled children and young people consistently say that leisure, play and holidays are the most important missing element in their lives. Parents strive to make opportunities for their disabled children to participate in leisure activities but are faced with many barriers including affordability and inaccessible facilities<sup>13</sup>.

<sup>12</sup> *Forgotten Families*, Contact a Family 2011  
<sup>13</sup> *Everybody Here?*, Contact a Family 2002

When asked about making further cuts to days out, parent carers often cited that this would really stop any form of joy in their children's lives. It would have a direct impact on isolation and emotional wellbeing for the whole family.

**Contact a Family is calling on local councils to offer a single assessment process that considers the financial wellbeing of the whole family, including a parent's ability to care and continue to provide care and access to work and leisure opportunities.**

### Charity grants help towards costs

Only 36% of families with disabled children have applied for a charity grant in the last year. Organisations like the Family Fund provide grants to help make life easier and more enjoyable for disabled children and their families. The majority of applicants (85%) that responded to our survey were successful in getting a grant. Many (42%) used the grant for specialist equipment or adaptations such as wheelchairs, car seats and beds. Others used the financial help to put towards a holiday (38%) or days out (23%) to help reduce their isolation.

More families with disabled children need to know about this vital source of financial support.

**Contact a Family is calling on all frontline professionals (such as GPs, health visitor and teachers) to proactively signpost families with disabled children to sources of financial support such as charity grants.**

Information on charity grants is one of the most common enquiries Contact a Family gets to our helpline, but we and other voluntary sector organisations need to work even harder to reach out to more families so we can help them access this type of support.

### Working and Childcare

It is widely acknowledged that families with disabled children face additional barriers to work<sup>14</sup>. Our survey results show that 74% of respondents indicated that someone in their family was in paid employment. However, only 17% use paid childcare, and when asked how much they paid per hour, this ranged from £2.50 to £20.

Some families with disabled children that responded to our survey are worried that welfare reforms will mean they are forced into going back to work and expressed doubt about being able to find employment suitable to fit in with caring responsibilities. We welcome the government's



commitment to make work pay through the introduction of the Universal Credit. We think it's important, however, that parent carers are not forced into work and their caring contributions are recognised across the benefits system, in the workplace and society as a whole.

**Contact a Family would like the government to set out how the Universal Credit will provide additional help to working families with disabled children by:**

- a carer's addition paid via the Universal Credit to working carers engaged in significant amounts of care is not restricted to entitlement based on earnings or hours worked (thereby removing the link to Carer's Allowance).
- a £20 per week enhancement in the earnings disregard for families with a disabled child. The amount of earnings ignored in calculating Universal Credit should be £20 per week (£1040 pa) higher than for a family in identical circumstances without a disabled child.
- recognition of the higher costs of childcare for disabled children via Universal Credit (for example, by covering at least 90 per cent of childcare costs for disabled children with an aspiration to increase this to 100 per cent as the economy improves)

The Government has said that people with 'regular and substantial' caring responsibilities will not have to look for work under Universal Credit, but this definition isn't clear as it is undefined. It is essential that carers keep their current protection from being forced to look for work. We call on the Government to clarify the definition of 'regular and substantial care'.

14 *Breaking Down Barriers* (Every Disabled Child Matters 2011).

Most parent carers find caring has an adverse impact on their own employment. Research shows that parent carers who care for 20 hours or more each week and who are also in paid work are more likely to work in low-paid jobs, are considerably less likely to be in managerial or senior positions, and are more likely to be in jobs very close to where they live<sup>15</sup>.

“Being a carer is TOUGH! Exhausting and living with disability is SO much harder than anyone can imagine! Many of the companies don’t understand what a CARER is! We just want them to make a few adjustments then they’ll have a committed worker for life...”

**Contact a family is calling on businesses and employers to provide greater flexible working to ensure parent carers have a real choice of combining work and caring.**

- We urge businesses and employers to introduce flexible working from the start of employment for carers.
- Employers can also advertise posts as flexible working, and where appropriate, discuss flexible working options at interview stage. Extending the right to request flexible working to all employees would reduce stigma and improve attitudes towards parents with caring responsibilities.

Evidence shows these flexibilities can reduce staff turnover and absences, thereby cutting employment costs. The evidence from employers themselves shows that it is rarely abused and increases loyalty and commitment<sup>16</sup>.

**Contact a Family is also calling on all childcare providers across the private and voluntary sector to continue to improve the inclusiveness of their settings so more disabled children can participate and their parents can work.**

<sup>16</sup> [www.employersforcarers.org/business-case](http://www.employersforcarers.org/business-case)

## Conclusion

*Counting the Costs 2012* shows the majority of families with disabled children continue to live under enormous financial pressure. Going without essentials and being forced to borrow money to buy food, heating and clothes is not something new created by austerity measures but an ongoing struggle.

Most are reliant on benefits but against the odds juggle work and huge caring responsibilities. This they get little recognition for; indeed many are facing great negativity associated with claiming benefits leveled at them in a personal way by others but also through negative media and government messaging.

Families with disabled children are already worn out worrying about money and now face the additional burden of cuts to their benefits. Many see this as another form of discrimination, on top of the practical and emotional challenges of raising disabled children. *Counting the Cost 2012* shows many are fearful for the future especially as changes to different benefits will have a cumulative effect on many households.

Previous *Counting the Costs* surveys showed that families with disabled children find the benefits system complex and difficult to navigate and Contact a Family welcomes the Government’s determination to create a benefit system that is simpler, easier to understand, and with greater incentives for those who are able to work. However, the need to reduce the budget deficit has left many families with disabled children feeling the government is unfairly targeting cuts on them.



<sup>15</sup> *Managing more than Most* (ACE National led by Carers UK 2006)

The Government's proposal to halve the basic disability addition paid in respect of a disabled child via the Universal Credit is almost certain to add to the financial hardship already experienced by families with disabled children.

**"I am furious that the Welfare Reforms and the lack of resources at local authority level have left families with disabled children fighting each other - all of us desperate for what money there is left."**

Recently, the government took the much-welcomed opportunity to exempt many carers from a change to working tax credits (WTC) 16 to 24 hours rule, due to their substantial caring responsibilities.

**"Thank you so very much for this exciting news, we would have been pushed even further into poverty, as we already really struggle to survive. I feel that a huge financial weight has just lifted from my shoulders and I'll be able to sleep better without the need to worry about the future as a family."**

**Lesley, mother of Bailey who has a range of disabilities on hearing about WTC exemption for carers**

We urge the government to take the opportunity through welfare reform regulations to protect financial support for all families with disabled children.



## About Contact a Family

### Campaigning

We campaign for rights and justice for all families with disabled children.

### Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

### Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

### Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

### Medical information

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 440 conditions and UK support. Each entry provides an overview of the condition with details of support groups where available.

### One-to-one support groups

We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

### Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

## Getting in contact with us

**Helpline 0808 808 3555**

Open Mon-Fri; 9.30am - 5.00pm

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