

## Help us reveal the true picture of family finances in the UK

Contact a Family is calling on mums, dads and other family members who care for children and young people with additional needs or disabilities to take part in important research about family finances and the impact of welfare reforms.

Counting the Costs 2014 is a repeat of our flagship survey and report that we've carried out every two years since 2008. In 2012, we found that one in seven families with disabled children were missing meals and one in six can't afford to heat their homes. Since then, many of the government's planned welfare cuts have been implemented, as the biggest shake up of the UK's benefits system in 30 years continues.

This means that your responses to this survey will give us a unique snapshot of families' current financial situation and whether it is getting better or worse.

By filling out the survey you will be helping us to raise awareness and lobby for change - particularly as welfare reforms continue to hit families with disabled children hard. This year's Counting the Costs is also particularly important as we try to influence party manifestos ahead of the next election in May 2015.

The survey which should not take more than 20 minutes. The deadline to complete the survey is the end of May 2014.

If you would like a hard copy of the survey or help completing the survey please contact us on 020 7608 8742.

## About you and your family

### \*1. In relation to your child or children with additional needs, disability or health condition are you the:

- Mother
- Father
- Grandmother
- Grandfather
- Foster carer
- Other (please specify)

### \*2. How old are your disabled children?

	0-5	6-15	16-19	20+
Disabled child 1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disabled child 2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disabled child 3	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disabled child 4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disabled child 5	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### \*3. For each child do you get Disability Living Allowance (DLA) or Personal Independence Payment (PIP)?

	DLA	PIP	In process of claiming/awaiting decision	No
Child 1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 3	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child 5	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### 4. If not, why? (Tick all that apply)

- Claimed in the past but refused benefit
- Have never heard of DLA/PIP
- Assumed that I had too much income or capital
- Assumed that any DLA award would be deducted from my other benefits
- Did not think my child's disabilities were severe enough
- Thought my child was too young to claim
- Thought I had to wait for a diagnosis
- Never found the time to complete the form
- Claim form too difficult to complete
- I could not get help to complete the form
- Felt uneasy claiming benefits for my child
- Someone told me I would not be eligible

Other (please specify)

#### \*5. How many other children live in your household?

- 0
- 1
- 2
- 3 or more

#### \*6. Do you or your partner (if you have one) have a disability or health condition?

	Yes	No
You	<input type="radio"/>	<input type="radio"/>
Partner	<input type="radio"/>	<input type="radio"/>

#### \*7. Are you a lone parent/grandparent?

- Yes
- No

**\*8. Where do you live in the UK?**

- Northern Ireland
- Scotland
- Wales
- East of England
- East Midlands
- London
- North East England
- North West England
- South East England
- South West England
- West Midlands
- Yorkshire & the Humber

**9. Which of these ethnic groups do you consider you belong to? (Please select one option)**

- White British
- White Irish
- Gypsy or Irish Traveller
- Asian
- Black/African/Caribbean
- Other ethnic group
- Mixed ethnic background

## Extra Costs

Families with disabled children often face extra costs linked to caring for their disabled children - like higher energy bills-that other families don't have. We want to find out more about these extra costs and how they affect your family finances.

### \*10. How much on average do you pay on costs directly linked to your child's disability/condition per month?

- £0-£99
- £100-£199
- £200-£299
- £300-£399
- £400-£499
- £500-£1000
- £1000 plus

### \*11. Consider the list of disability related costs listed below. Of the costs listed what are the top 3 in terms of their impact on your family finances?

	1st choice	2nd choice	3rd choice
Higher heating and utility bills	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Additional transport costs e.g. Extra petrol costs, taxis fares	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Costs of adapting home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost of adapting car eg specialist car seats etc	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More frequent washing/changing bedding and clothes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist toys, books, games	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist foods, clothing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Replacing damaged household goods/toys/clothing etc	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Charges for care services/staff/therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Higher insurance costs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### \*12. Do the disability benefits that you receive cover the extra costs linked to your child's disability/condition or additional needs?

- Yes
- Partly
- No

**13. What would make the biggest difference to helping you cover the extra costs?**

**(Choose only one)**

- Advice so I can claim benefits and other entitlements
- Increase in DLA or PIP
- Increase other disability and carers benefits
- Discounts by energy and utility companies
- More help from local authority/NHS
- Help so I can get back to work
- Other (please specify)

## Going without

**\*14. In the last 12 months, have you gone without something because of a lack of money?**

Yes

No

## More about going without

### \*15. What have you gone without? (Tick all that apply)

- Food
- Heating
- Childcare
- Leisure/days out
- Holidays
- Adaptations or specialist equipment
- Clothes
- Toys
- Bedding
- Car/car repairs/fuel for car
- Hospital visits/medicines
- Therapies

Other (please specify)

### 16. How often have you and your family gone without the following due to a lack of money:

	Daily	Once of week	Once a month	A few times a year	Never
Food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Days out	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fuel for the car	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist equipment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**\*17. What impact is going without having on you and your family? (Tick all that apply):**

- No impact
- Made me feel anxious/stressed
- Made me unwell/affected my health
- Made my child's condition worse
- I've borrowed from friends or family to make ends meet
- Caused arguments with my partner/children
- Caused my marriage/relationship to breakdown
- Meant my children had to go without something
- Needed to ask for help from social services
- Meant I've fallen behind with my rent/mortgage payments
- Forced to sell or pawn something
- Forced to move home
- Needed to use a food bank
- I've applied for a charity grant
- Other (please specify)

## Getting into debt

**\*18. In the last 12 months have you taken out a loan?**

Yes

No

## About your loans

### 19. What type of loan(s) have you taken out in the last 12 months? (Tick all that apply)

- Bank loan
- Internet/Quick cash loan/Pay day loan
- Unlicensed moneylender (loan shark)
- DWP budgeting loans
- Family or friends

Other (please specify)

### 20. How many loans have you taken out in the last 12 months?

- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 +

## 21. What have you needed the loan(s) for?

- Food
- Heating
- Childcare
- Leisure/days out
- Holidays
- Clothes
- Toys
- Bedding
- Car/car repair
- Adaptations or specialist equipment
- Therapies/medicines/care services or staff
- Council tax/rates
- To cover other loans/bills
- Other (please specify)

## Missed payments

**\*22. In the last 12 months have you fallen behind on any payments (gas, electric, credit card, council tax etc)?**

Yes

No

## Falling behind with payments

### \*23. If yes, what payments have you fallen behind with?

- Utilities (gas, electric, water, phone and internet)
- Council tax/rates
- Mortgage/rent
- Credit cards/bank loans
- Payday or other high interest loans
- Childcare costs
- Family or friends loan
- Catalogue payments
- Other (please specify)

### \*24. In the last 12 months have you been threatened with court action for failing to keep up with payments?

- Yes
- No

### 25. If yes, what payments have you failed to make that has resulted in court action?

- Utilities (gas, electric, water, phone and internet)
- Council tax/rates
- Mortgage/rent
- Credit cards/loans
- Childcare costs
- Family or friends loan
- Catalogue payments
- Other (please specify)

**\*26. What impact is getting into debt or falling behind with payments having on you and your family? (Tick all that apply):**

- No impact
- Made me feel anxious/stressed
- Made me unwell/affected my health
- Made my child's condition worse
- Caused arguments with my partner/children
- Caused my marriage/relationship to breakdown
- Needed to ask for help from social services
- Meant my children had to go without something
- Meant I've fallen behind with my rent/mortgage payments
- Forced to sell or pawn something
- Forced to move home
- Forced my child to change school
- Needed to use a food bank
- I've applied for a charity grant
- Other (please specify)

## Welfare reforms

**\*27. Has your family's income been affected by any of the changes to the benefits system in the last 12 months?**

- No
- Yes – I'm worse off
- Yes - I'm better off
- Don't know - I'm confused about changes



## Impact of welfare reforms

**\*28. If you have been affected by welfare reforms in the last 12 months, by how much per week are you worse off?**

- under £10
- £10-£19
- £20-£29
- more than £30
- not sure

**\*29. If yes, which of the following changes to the benefits system has affected you?**

- Housing benefit size rules-social landlord (i.e the bedroom tax)
- Housing benefit size rules-private landlord (i.e local housing allowance)
- Reduction in help with council tax as result of local scheme replacing council tax benefit
- Loss or cut in benefit due to DLA being replaced with PIP
- Benefits cap of £26,000
- Cut in % of childcare costs met by tax credits
- Other tax credits changes
- Ending Child Benefit for higher rate tax payers
- Scrapping Employment Support Allowance (ESA) in youth
- Time-limiting contributory ESA to 12 months for some claimants
- Unable to access one-off grants since Community Care Grants scrapped
- 2 year waiting period before a DLA/PIP can be claimed if returning to or entering UK
- Don't know

Other (please specify)

## Bedroom tax and benefit cap questions

Complete these questions if you have been affected by changes to housing benefit size criteria rules in private rented or social housing (ie the bedroom tax) or the benefit cap

### 30. How much was your Housing Benefit cut by per week?

- Less than £10
- £11 - 24
- More than £25

### 31. Have you heard of discretionary housing payments (DHPs)?

- Yes
- No

### 32. Have you applied for DHPs

- Yes
- No

### 33. Were you awarded DHPs

- Yes
- No

### 34. Did the DHP cover all of the Housing Benefit you lost?

- Yes
- No

### 35. How long were you initially awarded DHPs for:

- Less than 6 months
- 6 months
- 7-12 months
- more than a year

### 36. Did your DHPs stop after a temporary period

- Yes
- No – they were continued

## Welfare reforms and looking to the future

### \*37. What impact have benefit changes had on you and your family (Tick all that apply):

- No impact
- Made me feel anxious/stressed
- Made me unwell/affect my health
- Made my child's condition worse
- I've needed to borrow from friends or family to make ends meet
- I've needed to take out a bank loan
- I've needed to take out a payday loan
- Needed to ask for help from social services
- Caused arguments with my partner/children
- Caused my marriage/relationship to breakdown
- Meant my children had to go without something eg days out, presents, meals etc
- Meant I've fallen behind with my rent/mortgage payments
- Forced to sell or pawn something
- Forced to move home
- Forced my child to change school
- Needed to use a food bank
- I've taken out a charity grant
- Other (please specify)

### \*38. How do you see your financial situation changing in the next 12 months?

- Improving
- Same
- Worse

**39. If you answered 'worse', what are the 2 main reasons?**

	First	Second
Economic situation/cost of living	<input type="radio"/>	<input type="radio"/>
Benefit cuts due to welfare reforms	<input type="radio"/>	<input type="radio"/>
Expenses associated with your disabled child	<input type="radio"/>	<input type="radio"/>
Difficulty of working and being a carer	<input type="radio"/>	<input type="radio"/>
Debt	<input type="radio"/>	<input type="radio"/>
Other family circumstances changing	<input type="radio"/>	<input type="radio"/>

**\*40. Do you understand how future changes to the benefits system will affect your family's finances?**

- Yes
- No, I'm confused about changes
- Not aware of future changes

**\*41. How do you feel about the following benefit changes?**

	Not worried	Worried	Very worried	Don't know
Replacement of DLA for 16-64 year olds by PIP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Universal Credit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**42. Is there anything else you would like to tell us about benefit changes?**

**\*43. Have you received help from Contact a Family on claiming your benefits or other entitlements?**

- Yes
- No

## Attitudes towards claiming benefits

In 2012, our Counting the Costs research revealed that some families with disabled children were experiencing negative attitudes from other simply because they claim the benefits they are entitled to. We want to find out more about this.

**\*44. Do you feel the stigma of claiming disability benefits has increased in the last 2 years?**

- Yes
- No
- Don't know

**\*45. According to the British Social Attitudes Survey, attitudes of the British people are hardening towards benefits and those claiming them.**

**What has your experience been in the last 2 years:**

- Not affected
- I stopped claiming benefits for my disabled child because of people's negative attitudes
- I stopped claiming benefits for myself because of people's negative attitudes
- I don't tell people that I claim benefits
- I've received verbal insults from friends/family members because I claim disability benefits
- I've received verbal insults from neighbours/people in the street because I claim disability benefits
- Other (please specify)

**46. Please tell us more about your experiences.**

## Your family income and work

We want to understand a bit more about your family finances, however you may feel some of the information in this section is personal. Any information given will be confidential and anonymous.

### 47. What is your annual family income?

- Under £15,000
- £15,000 - £20,000
- £20,000 - £30,000
- £30,000 - £40,000
- £40,000 - £50,000
- £50,000 plus

### 48. Does someone in your household have a pension?

- Yes
- No

### 49. Does your household have more than £16,000 of savings?

- Yes
- No

### 50. Is your current home:

- Rented from a private landlord
- Rented from a social landlord (such as the council, housing association, housing executive)?
- Owner occupied
- Temporary accommodation
- Shared ownership

Other (please specify)

### \*51. Is someone in your household in paid employment?

- Yes
- No

### \*52. Do your caring responsibilities mean you or a partner are unable to work as much as you would like?

- Yes
- No

## Using childcare

Childcare is important to help parents work, despite the increase in childcare, the cost of childcare for disabled children remains a big problem. We want to find out more.

### \*53. Do you use paid childcare for your disabled children (such as a nursery, after school club)?

- Yes
- No

### 54. If you use paid childcare for your disabled children, which of the following do you use?

- School nursery
- Private nursery
- Before or after school club
- Childminder
- Nanny/home childcarer
- Specialist

Other (please specify)

### 55. If you pay for childcare for a disabled child, how much do you usually pay per hour?

- Less than £5
- £5-£10
- £11- £15
- £16 - £20
- More than £20

### 56. If you don't use paid childcare for your disabled child, why is this?

- My family and friends help
- It's too expensive
- Childcare staff don't have the experience to look after my disabled child
- Told my child needed 1:1 support and funding wasn't available
- Told my child was a health & safety risk
- Don't know how to find the right childcare
- Other (please specify)

**\*57. Please tell us if you agree or disagree with the following statements:**

Agree

Disagree

Not sure

It is more difficult to find childcare for a disabled child than a child who is not disabled

It is more expensive to arrange childcare for a disabled child than a child who is not disabled

There is not enough choice of good quality childcare options if your child is disabled

I have found it difficult to combine working with looking after my child because of childcare problems

I have had to cut back my work or give up work because of childcare problems



## Help us campaign

We need your experiences to raise awareness with government and the media about the financial reality for families with disabled children across the UK.

We will use the findings from this survey to do this but we need your help to be a case study please volunteer.

**58. If you are happy to speak in the media to raise awareness of any of these issues please leave your name and contact details**

Name

Email Address

Phone Number

## Get advice today

Contact a Family provides advice, information and support to families with disabled children, whatever the child's disability or condition.

Make sure you are claiming every penny you're entitled to.

Call us on 0808 808 3555 or email us [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

Find out more about benefits and entitlements at [www.cafamily.org.uk](http://www.cafamily.org.uk)