



Counting the Costs 2012

The financial reality for families with disabled children in Scotland

"It's a vicious circle, there's never enough money to pay the weekly bills and things are getting harder. I've had to resort to using internet pay day loans regularly to make ends meet. It's the lesser of two evils – it's either use a quick cash loan or get charged for going overdrawn. I'm trying as hard as I can working, caring and being a mum, but feel like I'm constantly chasing my tail."

Mother from Dundee, son has Mosaic Down Syndrome

Key Findings, based on responses from 202 parent carers¹ across Scotland, (8.7% of total across the UK):

- 75% are working families – only 14% use paid childcare
- 26% care for more than one disabled child
- 24% are lone parents.

Overall, 82% have gone without something because of a lack of money, including:

- food – 19%*
- heating - 18%
- clothes - 61%
- days out/leisure – 85%
- specialist equipment/adaptations – 32%*

33% have taken out a loan,* (22% from a pay day, quick cash or loan shark) of which:

- 37% for food

- 34% for heating
- 25% for specialist equipment/adaptations
- 31% for days out.

43% have fallen behind with payments:

- 56% with utility bills
- 48% with council tax payments*
- 21% with the mortgage or rent

17% have been threatened with court action for failing to keep up with payments in the last 12 months.

Only 38% have applied for a charity grant, such as Family Fund. Of these applicants, 95% were successful - 55% were for holidays, 39% specialist equipment and 26% for days out.

58% think that their financial situation will get worse in the next 12 months – 82% citing welfare reforms as the main reason for this.*

¹ Respondents to this survey are parent carers. This includes mothers, fathers and grandparents of disabled children and young people

* Denotes where figure is higher than overall UK figure

Summary

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 many families with disabled children in Scotland. This is not a new situation created by the economic downturn or recession.

However, in 2012 Scottish families with disabled children are facing a new pressure on their incomes due to changes to the benefits system introduced by the UK government's welfare reforms. Our findings show Scottish families with disabled children are worried and often confused about these benefit changes. This is an unnecessary additional strain on top of the physical and emotional challenges of caring for a disabled child not experienced by other families.

Counting the Costs 2012 also reveals the level of stigmatization of families with disabled children across the UK. 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 is leaving many parent carers having to justify themselves and their disabled children as being disabled or worthy enough to claim benefits.

"I am fed up with people accusing me of making my son's disability up. Some even go as far as to accuse me 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."

Mother from Fife, son has global developmental delay

Money worries are putting huge emotional and mental strain on Scottish parent carers, pushing some to breaking point and putting family life at risk. As a result, Contact a Family, is calling for combined action by the Scottish Government, local authorities, energy companies and frontline professionals to make it better for families with disabled children and reduce the unacceptable persistent poverty they experience.

Recommendations

Contact a Family is calling on the Scottish Government and local councils to make it better for families with disabled children by:

- supporting the provision of vital specialist financial advice to enable families with disabled children to maximise income and reduce debt
- ensuring the availability of affordable, accessible childcare across Scotland. This would enable more parents with disabled children to work, increasing family income and helping to give children the best start in life
- prioritizing and addressing the unique financial changes facing families with disabled children through its Child Poverty Strategy.
- disregarding Disability Living Allowance (DLA) payments when calculating entitlement to discretionary housing payment (DHP) and treating families with disabled children as a priority group.

Contact a Family welcomes the commitment by the Scottish government and COSLA to protect the poorest from cuts to council tax benefit in 2013 – 2014 and the recent increase in money for short breaks through the *Take a Break* and *Better Breaks* funding programmes, and we urge the Scottish Government to continue this in future.

How Contact a Family can help

- specialist welfare rights advisors through our National Freephone helpline 0808 808 3555, make sure parents know about all the different financial help available and advice on how to claiming
- we produce range of guides with more detailed information on:
 - Benefits, tax credits and other financial assistance
 - Future benefit changes
 - Dealing with Debt
 - Claiming Disability Living Allowance for children
 - Working and childcare
- we can advise parents wanting to return to work on their employment rights and the impact working will have on their benefits
- we put families in touch with national condition support groups, who often provide families information and advice on claiming benefits specific to their child's condition

Getting in contact with us

Helpline 0800 808 3555

Web: www.cafamily.org.uk

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