



Counting the Costs 2012

The financial reality for families with disabled children in Wales

"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."

Mother from Wales, son has autism

Key Findings, based on responses from 152 parent carers¹ across Wales, (6.6% of total across the UK):

- 79% are working families – 13% use paid childcare
- 23% care for more than one disabled child
- 20% are lone parents.

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

- food – 19%*
- heating - 25%*
- clothes - 65%*
- days out/leisure – 87%
- specialist equipment/adaptations – 32%*.

29% have taken out a loan, (27% from a pay day, quick cash or loan shark*) of which:

- 25% for food

- 43% for heating*
- 36% for specialist equipment/adaptations*
- 21% for days out.

40% have fallen behind with payments:

- 66% with utility bills*
- 37% with council tax payments*
- 32% with the mortgage or rent*.

22% 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, 84% were successful - 43% for specialist equipment, 41% for holidays and 27% for days out.

64% think that their financial situation will get worse in the next 12 months – 77% 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

I've stopped eating every day, as I need the money for petrol so I can get to work. John needs specially-measured shoes which are very expensive. I've borrowed money from family to pay for food, gas and electric. I'm really worried about the future.

Mother from Wales, son has Duchenne muscular dystrophy

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 Wales. This is not a new situation created by the economic downturn or recession. Substantially more Welsh families with disabled children are going without necessities and taking out loans for specialist equipment/home adaptations essential to keep children safe compared to the overall UK figure.

In 2012, Welsh families with disabled children are facing new pressures on their incomes due to changes to the benefits system introduced by the UK government's welfare reforms. Our findings show families with disabled children in Wales are worried and confused about 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.

Money worries are putting huge emotional and mental strain on parent carers in Wales, pushing some to breaking point and putting family life at risk. As a result, Contact a Family, is calling on combined action by the Welsh government, local councils, energy companies, frontline professionals and welfare advice services 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 Welsh Government and local councils to make it better for families with disabled children by:

- ensuring the poorest families with disabled children are protected from the 10% cut to council tax benefits. This could be achieved by setting uniform council tax benefit schemes rather than devolve it down to Welsh councils
- prioritizing and addressing the unique financial challenges facing families with disabled children through its Child Poverty Strategy, Families First and Flying Start programmes
- disregarding Disability Living Allowance (DLA) payments when calculating entitlement to discretionary housing payment (DHP) and treating families with disabled children as a priority group
- putting pressure on energy companies to treat families with disabled children in the same way as pensioners and guarantee a payment of £120 payment next winter.

Contact a Family is also calling on all financial inclusion and welfare benefit schemes across Wales to be aware of valuable specialist financial support available for families with disabled children from charities such as the Family Fund and others.

How Contact a Family can help

- specialist welfare rights advisors through our UK-wide freephone helpline 0808 808 3555 can make sure parents know about all the different financial help available and advice on how to claiming
- we produce range of guides for parent carers, including:
 - Benefits, tax credits and other financial assistance
 - Future benefit changes
 - Dealing with Debt
 - Claiming Disability Living Allowance for children
 - Working and childcare
- giving advice to parents wanting to return to work including their employment rights and the impact 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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Registered in England and Wales Number: 1633333
Charity registered in Scotland Number: SC039169
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