



## COUNTING THE COSTS 2024

Online Survey



## Background and Methodology

- Contact campaigns tirelessly to improve support for UK families with disabled children and welcomes the increase in the Carer's Allowance in the latest Budget.
- However, so much has changed in the UK in the last few years and to inform current and future campaigns Contact has recently conducted its online Counting the Costs Survey.
- This 2024 survey achieved a huge response from 4,262 parents who have a disabled child/children between the ages of 0-25.
- All respondents live in the UK and are responsible for paying the household bills.
- Parents surveyed include 60% based in England, 8% in Scotland, 5% in Wales, and 3% in Northern Ireland and 24% did not respond to this question

## Technical notes

The survey was open to all qualifying parents who responded on the Contact website from 28 Aug – 30 Sept 2024.

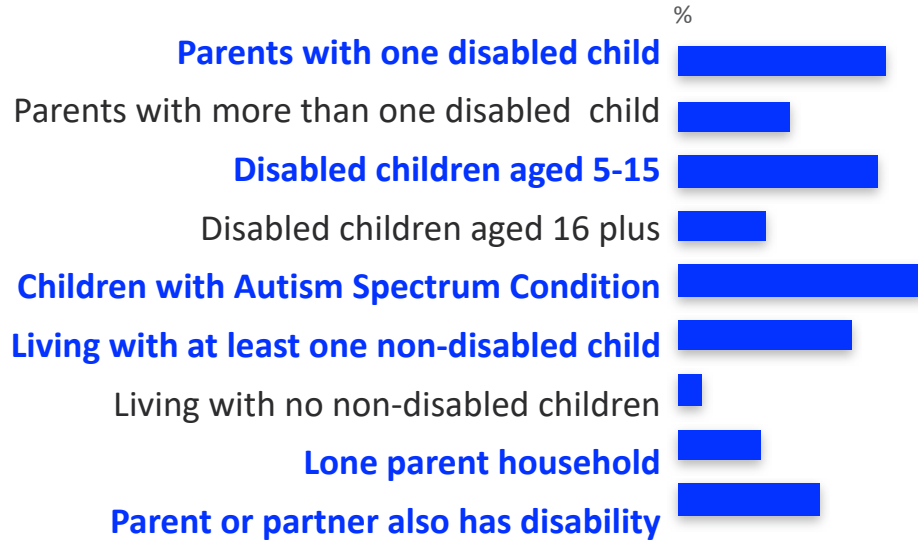
This is a self-selecting on-line survey and excludes anyone without internet connection.

NB – It should be noted that respondents could skip any questions they were not comfortable answering and those that skip have been recorded in the data as no response given but these percentages have not been added to these charts.

Few statistically significant differences were found between family experiences in the different nations of the UK, but topline figures for each nation are provided separately.



- This survey of 4,262 parents with disabled child/ren reveals:

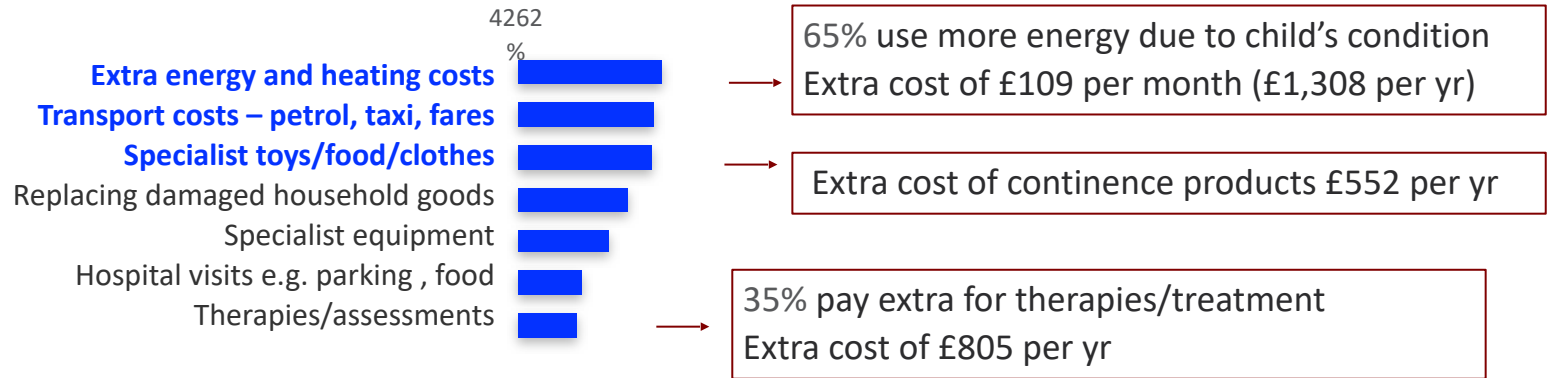


- 65% of parents have one disabled child.
- 62% of disabled children are aged 5-15 and 28% aged 16 plus.
- Although these children can have a range of conditions, more than three quarters (76%) have Autism Spectrum Condition.
- On average these children live with at least one other non-disabled child – only 8% live without another non-disabled child in the household.
- Just over one in four (26%) are lone parents and 44% of parents/ partners also have a disability or health condition.



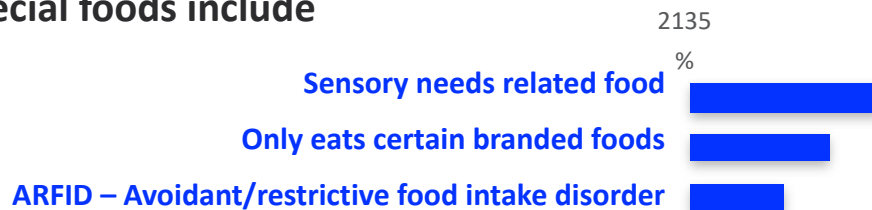
- On average parents are spending an extra £322 per month (£3,864 per year) on costs directly related to their child’s condition.

## Parents spend most money on:



- Overall parents spend on average 33% of their monthly income on food.
- Half (50%) of these children need a special diet/food for their condition.

## Special foods include



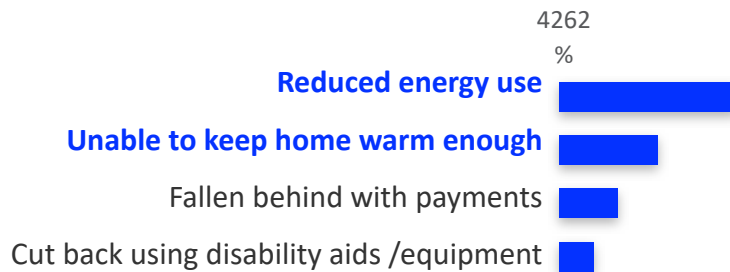


- Overall parents have paid on average £2,511 for heating and energy in last 12 months

The majority, 63% pay by monthly direct debit

But 13% pay by a prepayment method

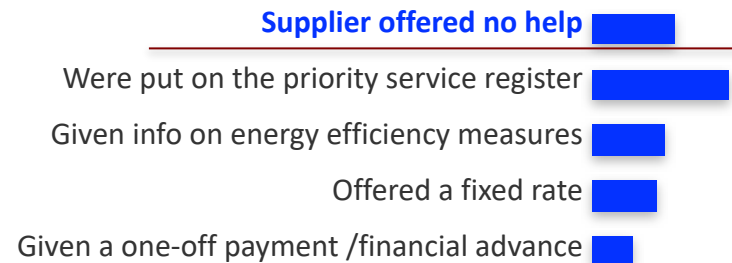
### Impact of these extra costs:



### 16% of parents the bill contacted their energy supplier for help as unable to pay their bill.

Of those:

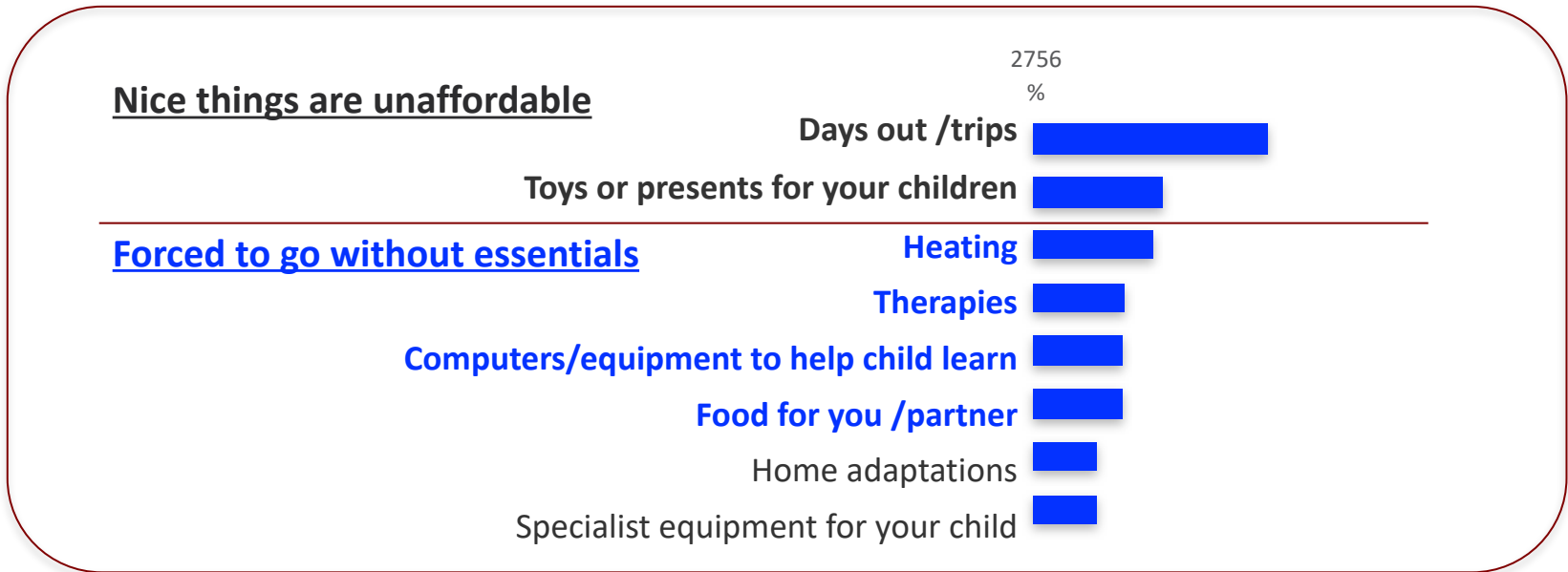
701%



- The worry of these extra energy costs adds to the stress levels for 77% of these families, increases isolation for 55%, and 47% found it worsened the parent’s and/or the child’s health conditions.



- **Almost all parents (95%) are worried about paying their bills and finding everything so expensive these days.**
- **65% of families have no option but to go without many things due to lack of money.**

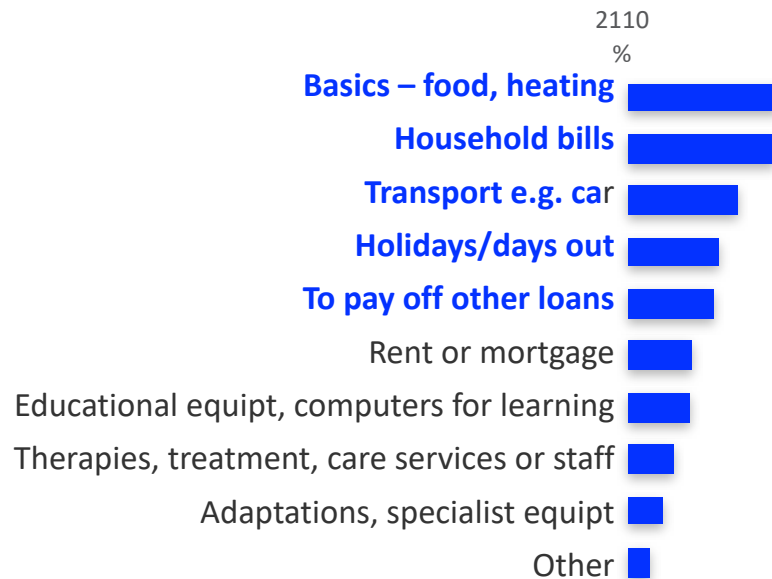


- **And 14% have had to use a food bank in the last year.**

I cried whilst there. I felt so ashamed it had got to that point, because I am being forced to pay (out of my benefits, as a single, disabled carer) for all the therapies that my child needs. (199)



- **Half (50%) of parents have got into debt or borrowed money in the last 12 months.**
- **And loans are needed mostly for essentials:**



In 2k of debt on electricity and buy oil when we need it (437)

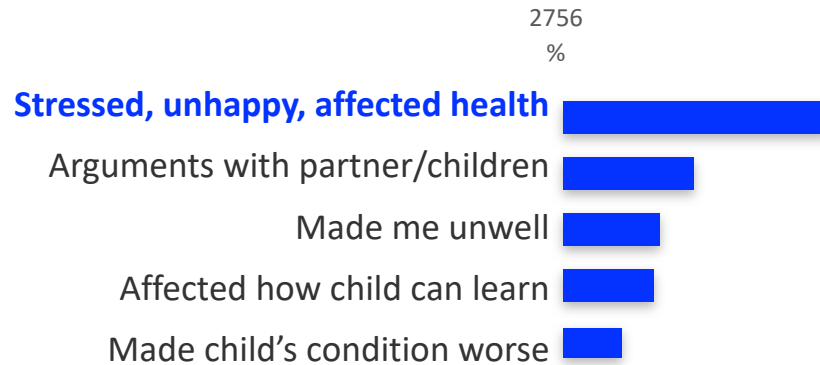
Specialist buggy (2531)  
Fridge and cooker (2539)  
New boiler - lived with a broken boiler for over a year, tried to save but couldn't so had to borrow it (2547)

I have too much debt to pay decent amounts monthly (2294)

My son had to wait 7 months without his full universal credit payment. We were being threatened with bailiffs from the energy company. (346)



- **Understandably almost all (90%) of parents find having to go without due to lack of money very stressful.**
- It can also result in 44% having family arguments, 33% of parents becoming unwell, and for 20% it can make their children’s condition worse.



It's very isolating. Especially as a single parent on Universal Credit, it's becoming increasingly hard to live month to month even on the basics (165).

Low self esteem, feeling like a failure but mostly really angry at society and the Local Authority in particular. (564)

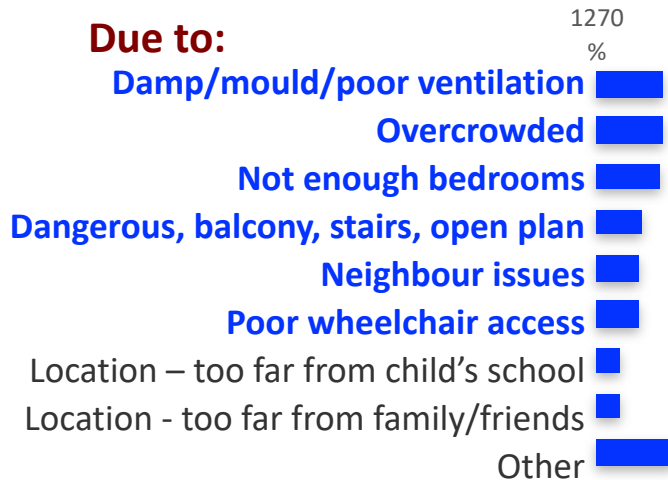
Had to explain to my other kids that they had to go without to buy equipment for their sister. (67)



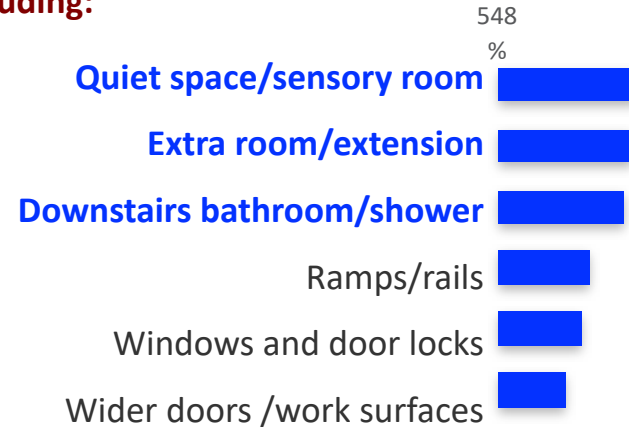


## • 30% of parents have homes that don't meet their child's needs

Due to:

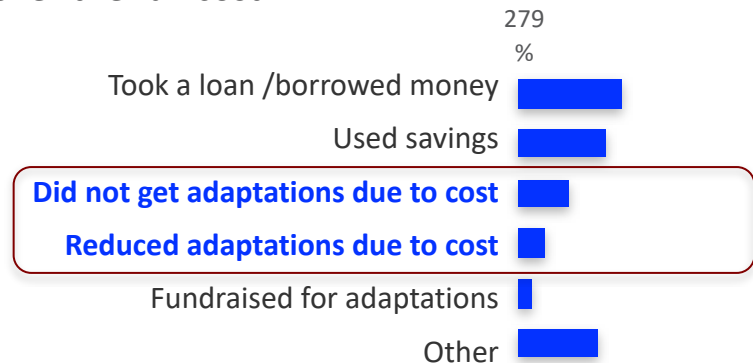


And of those, 43% homes need some adaptations including:



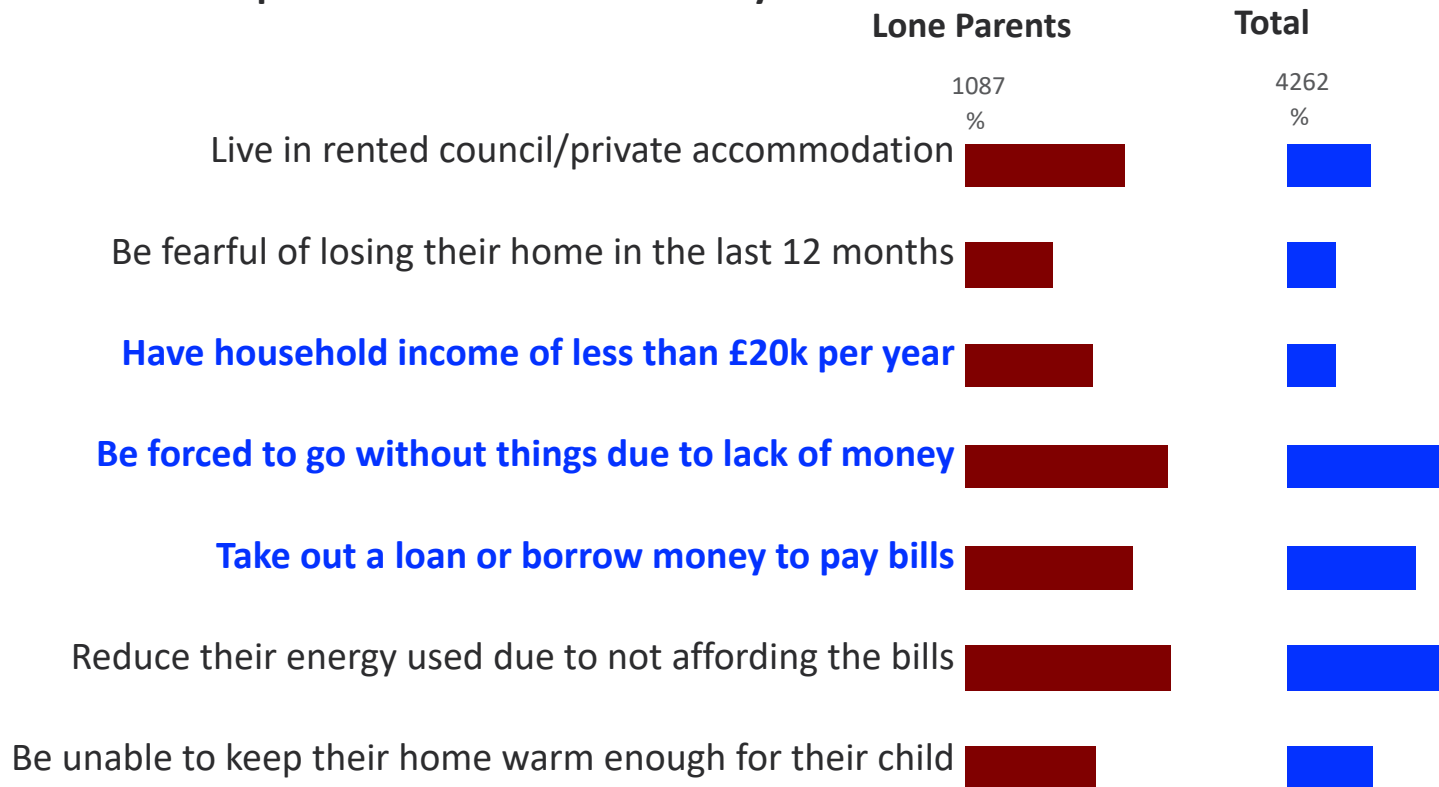
## Disability Facilities Grant (DFG)

- 27% are unaware of the DFG; only 12% have claimed DFG. Of those, 43% rated the experience of applying poor. Over half (57%) said the DFG did not cover the full costs of adapting their home and on average parents needed an extra £7,391 to cover the full cost.
- Of those needing more money to cover costs:





- In total 1087 (26%) of the parents that responded said they were Lone Parents
- Results clearly show that the pressures of caring and paying for disabled children are so much harder for lone parents
- Lone parents are much more likely to:



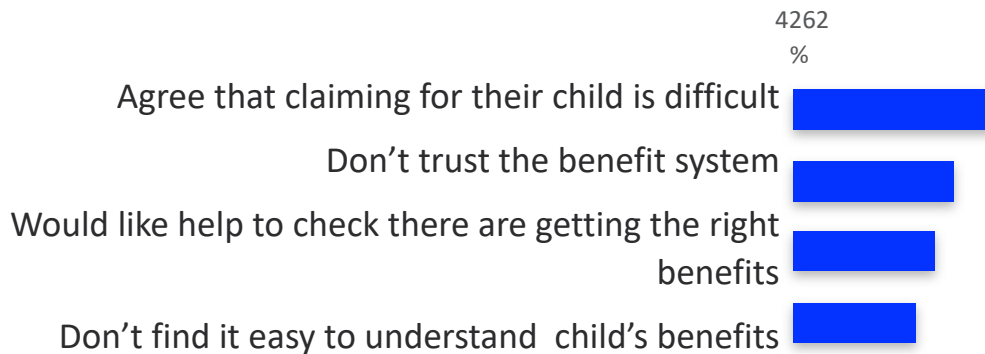


- Overall, 52% of households have someone in paid employment and the average household income is £33,013 per year.
- **However,**
  - 23% have no one in the household in paid employment**
  - 19% have a household income of less than £20k per year**
- **Caring responsibilities means the majority (62%) of parents/partners, had to give up a paid job or reduce hours.**

On average these parents have lost £21,174 of income per year
- **Although welcoming the recent Budget increase in money Carers can earn and the hours can work before losing benefits, the issues of overpayments will still be a worry for parents.**
- Currently 11% say they have been overpaid this allowance by the DWP in the last year and of those:
  - 73% said it was because of their earnings
  - On average these parents had to repay the DWP £1,045 which caused 88% of them stress/anxiety and anger

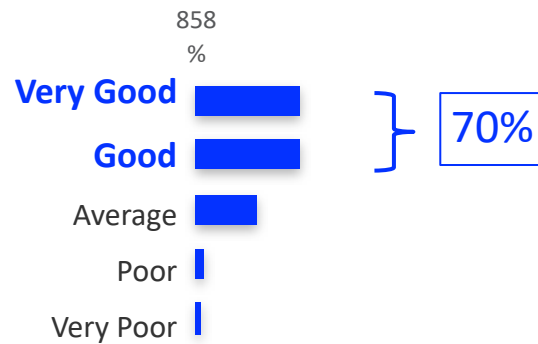


- **One third (34%) say they have at least one child who gets DLA/PIP/Scottish Child or Adult Payment BUT is not at the highest rate for personal care or enhanced rate.**
- Overall, 48% of parents with disabled children said they had tried to claim Universal Credit. Of those:
  - 43% said they had claimed after receiving a Migration Notice from other benefits
  - 9% are affected by the 2-child limit under Universal Credit
- Claiming benefits has long been difficult for parents with disabled children:

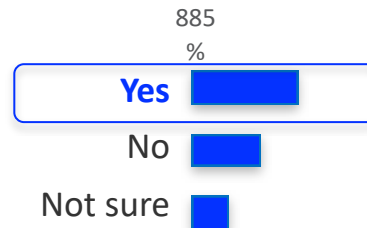




- One in five parents with disabled children (21%) have used the Contact helpline or website for advice on financial benefits and of those:
- **The majority (70%) rated the CONTACT helpline or website experience Very good/Good**



- **Following advice from the CONTACT helpline or website, 49% successfully claimed a benefit or challenged a decision**





# Much more needs to be done!

- Caring for a disabled child involves many extra costs. Most parents pay more for energy, food, and other costs relating to the child's condition. They also have costs those without disabled children don't have, such as therapies and continence products
- Significant numbers of these parents are living in poverty and are forced to go without many essentials and/or get into debt to pay their bills.
- This poverty causes very high levels of stress which impacts the health and wellbeing of both the parents and their disabled children.
- These pressures are intensified by unsupported caring responsibilities, such that parents have no choice but to limit their working hours or stop working altogether.
- Recent increases to the Carer's Allowance working hours are welcomed, but parents will continue to be anxious about losing benefits if these levels are exceeded.
- Clearly much more needs to be done to address the poverty and isolation facing many of these parents with disabled children and particularly lone parents.
- Results indicate Contact may benefit from looking more closely at the different needs of parents with neurodiverse conditions and physically disabled children.

# contact

*For families  
with disabled children*



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