



Family Poll December 2022  
- Findings



**Family Fund**  
Helping disabled children



# Family Fund

Helping disabled children

**Our purpose** is to improve the lives of low-income families raising disabled or seriously ill children and young people.

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**Our mission** is to provide items and services to all low-income families in the UK raising disabled or seriously ill children, that they could not otherwise afford or access, and that help improve their quality of life, realise their rights, and remove some of the barriers they face.

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**Our vision** is that all families raising disabled or seriously ill children have the same choices, quality of life, opportunities and aspirations as other families.







## Methodology

The data in this report comes from our quarterly Family Poll. The purpose of the poll is to better understand and track the needs and challenges families on low-incomes raising disabled children face.

Families were eligible to participate if they had not received a grant from Family Fund in the previous 12 months, and had not been invited to take part in Family Poll in the previous 12 months.

A random sample of eligible families were invited to take part. As a thank you for their participation, participants were offered the chance to enter a draw for a £100 Argos voucher.

The initial invitation was sent out on 7<sup>th</sup> December 2022, with a follow up three days later to recipients who hadn't opened the email, with a final follow up on the 19<sup>th</sup> December of parents/carers who hadn't opened either of the two previous emails.

This resulted in an achieved sample size for this poll of 1,055 families.





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The profile of the families who took part in the Family Poll

# 1. Profile of families

Families who took part in Family Poll are a cross section of the families Family Fund works with

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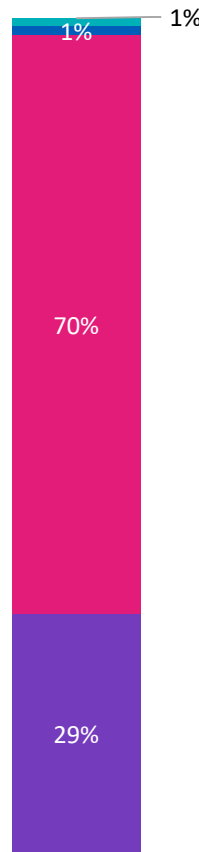
# Who are the families who took part in Family Poll?

1,500

Children with disabilities or serious illnesses



0-4 yrs    5-10 yrs    11-15 yrs  
16-17 yrs    18-24 yrs



Female  
Male  
Prefer not to say  
Prefer another term

1,055

Responses from families

1,693

Adults living in the households

1,131

Children without disabilities or serious illnesses

4

Average family size

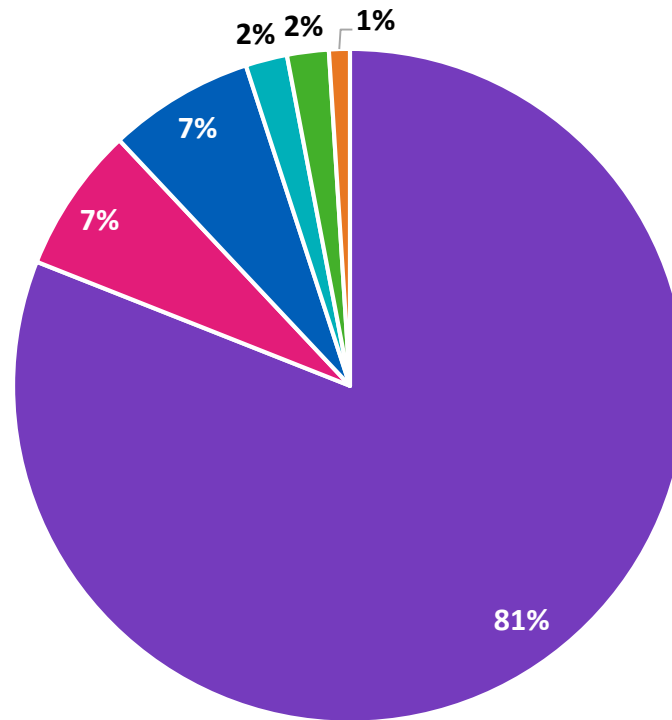
47%

Of families that responded were **single adult households**



# Who are the families who took part in Family Poll?

Please describe your ethnic group (n=1,055)



■ White ■ Black or Black British ■ Asian or Asian British ■ Mixed ■ Other ■ Prefer not to say

## £17,098

The mean **annual household income** reported by families



## The financial cost of caring

# 2. Reduced incomes

For many families raising disabled children, parents and carers' ability to earn an income is significantly limited by their commitment to caring for their child.

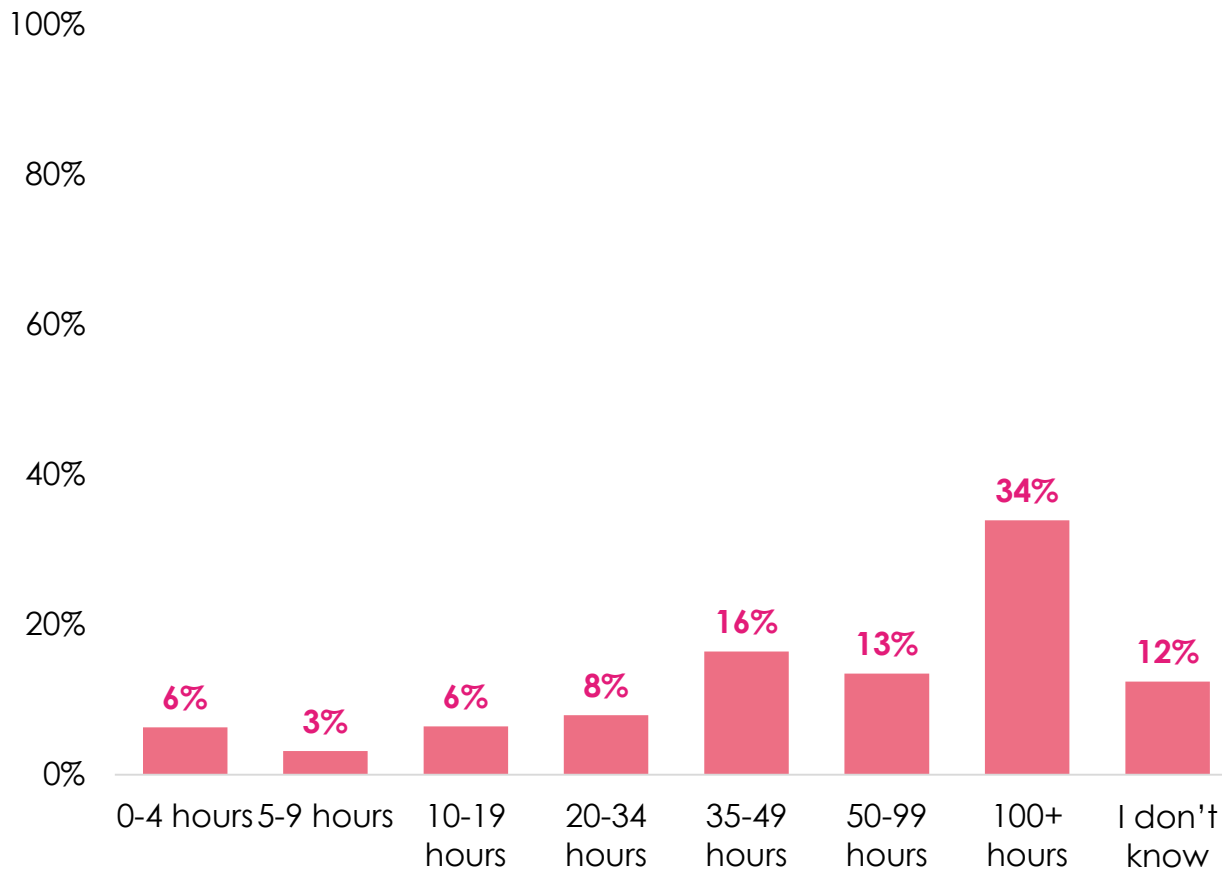
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# Caring

“About how many hours a week, on average, does each adult living in your household spend providing help for or looking after your disabled children?” (n=1693)



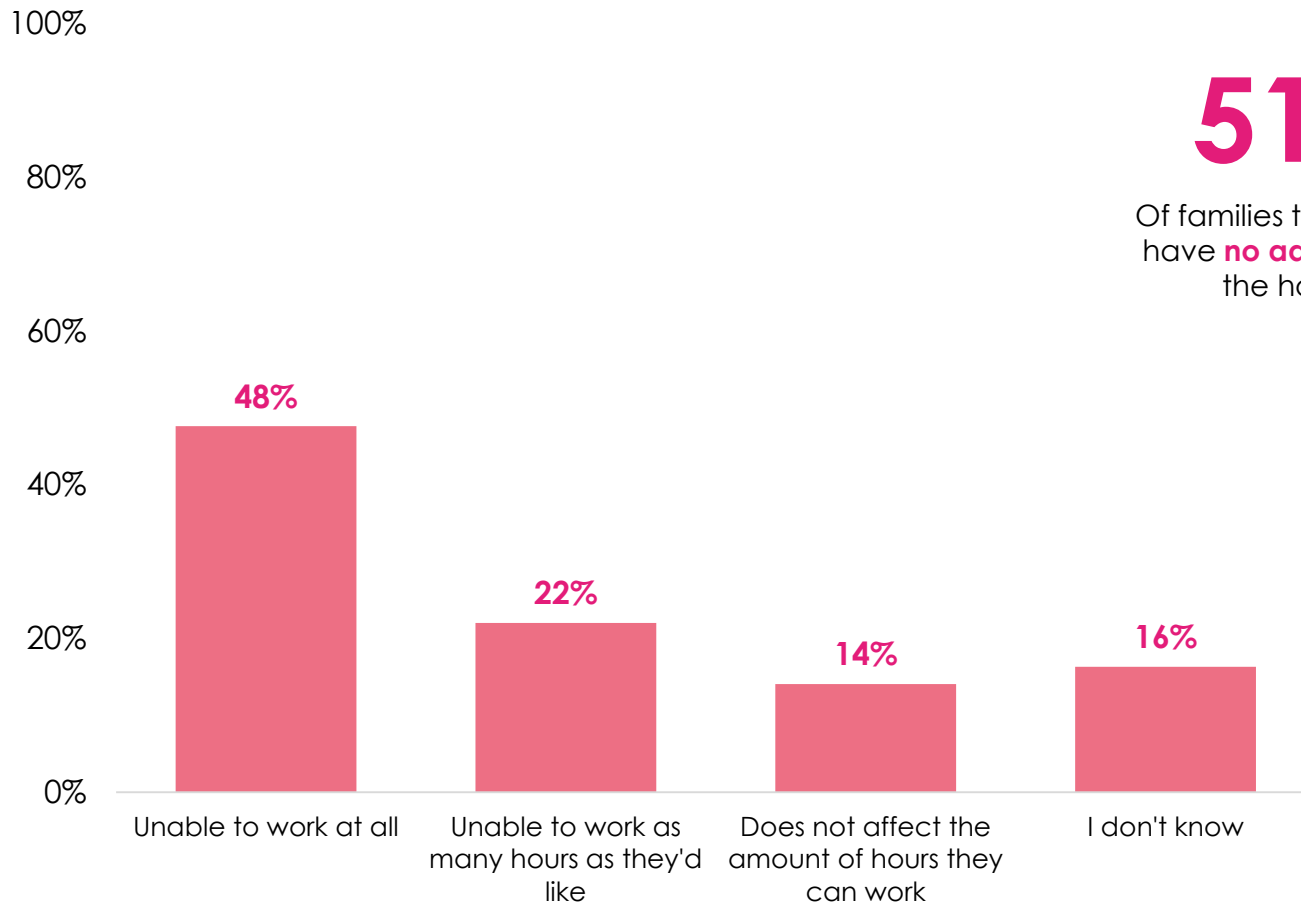
## 56 hours

a week **average spent caring** for their disabled children.



# Working and caring

“How does the caring responsibilities for your disabled child taken on by each adult living in your household impact on the paid employment they are able to do?” (n=1693)



**51 %**

Of families that responded have **no adults working** in the household



# Family's experiences of working and caring

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*"We need more chance in employments and flexible hours"*

*"I wish more jobs were family friendly so that I could earn an income around my child's needs"*

*"Employers not making it easy to work whilst being a carer. Carers' rights need improving. Carers allowance and earning allowance is too low"*

*"Raising and caring for three autistic children can be very isolating and lonely at times. My husband left his job in March of this year to help me care for them as I could no longer cope on my own. My physical and mental health was significantly affected"*



## The financial cost of caring

### 3. Access to other care

Even when families would like their child to be cared for by someone outside the household this isn't always available. This further limits their ability to earn additional income.

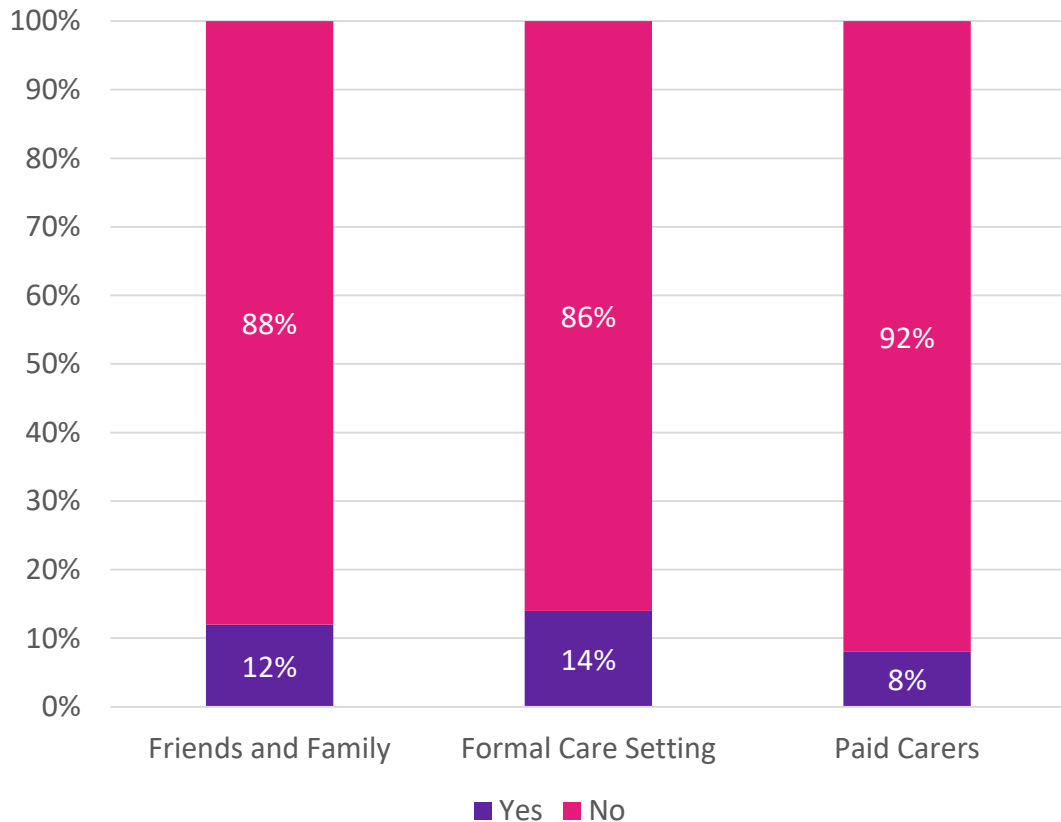
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# Access to care outside the household

Who, outside your household or an education setting, cares for your disabled child? (n=1,055)



8%

Of families that responded had access to as much **care outside the household** as they wanted

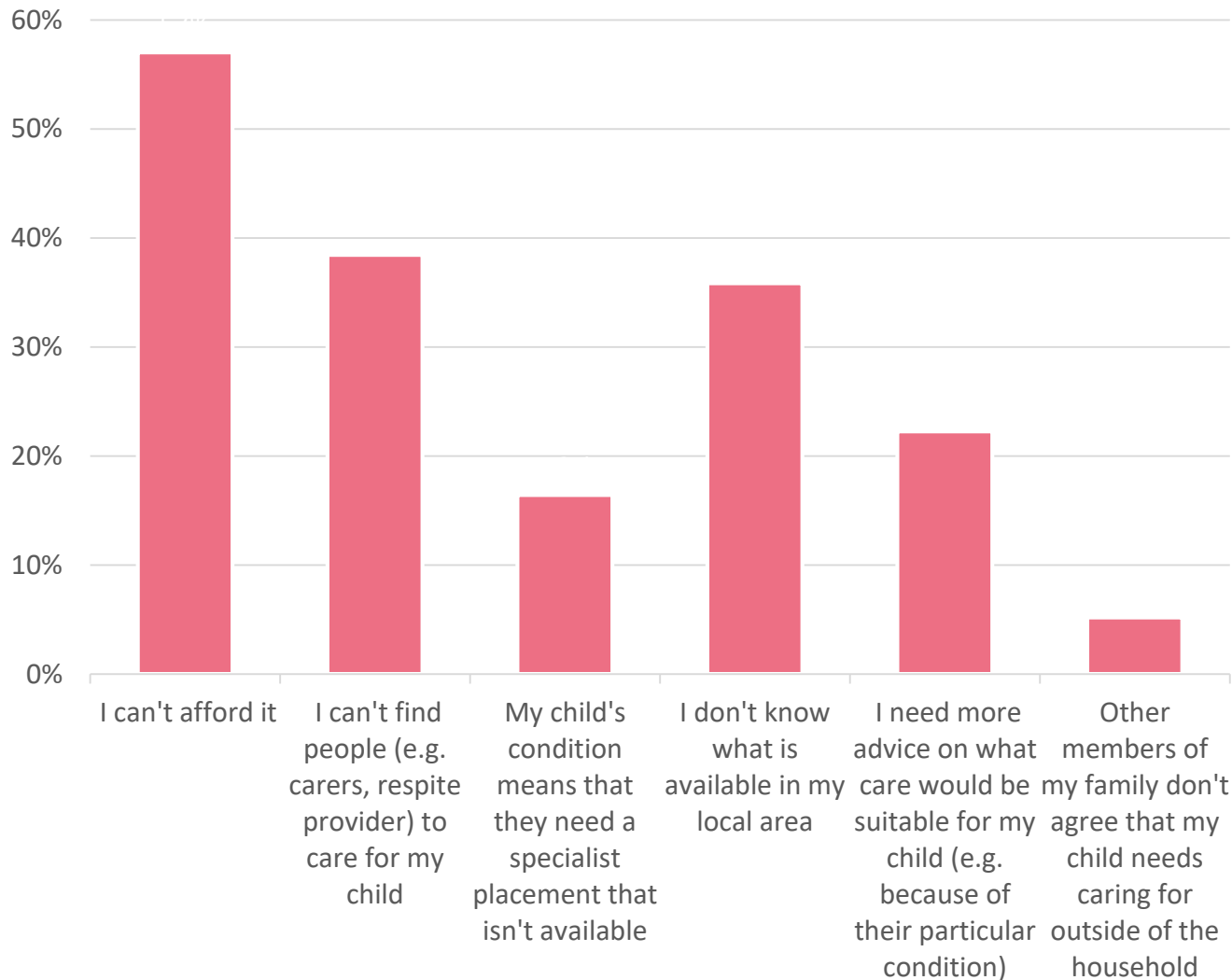
27%

Of families that responded didn't want **care from outside the household** for their child



# Unmet need for care

Why are you unable to access care for your disabled child outside your household? (n=463)



44%

Of families that responded had **unmet care needs** for their child outside the household



## The financial cost of caring

# 4. Increased and extra costs

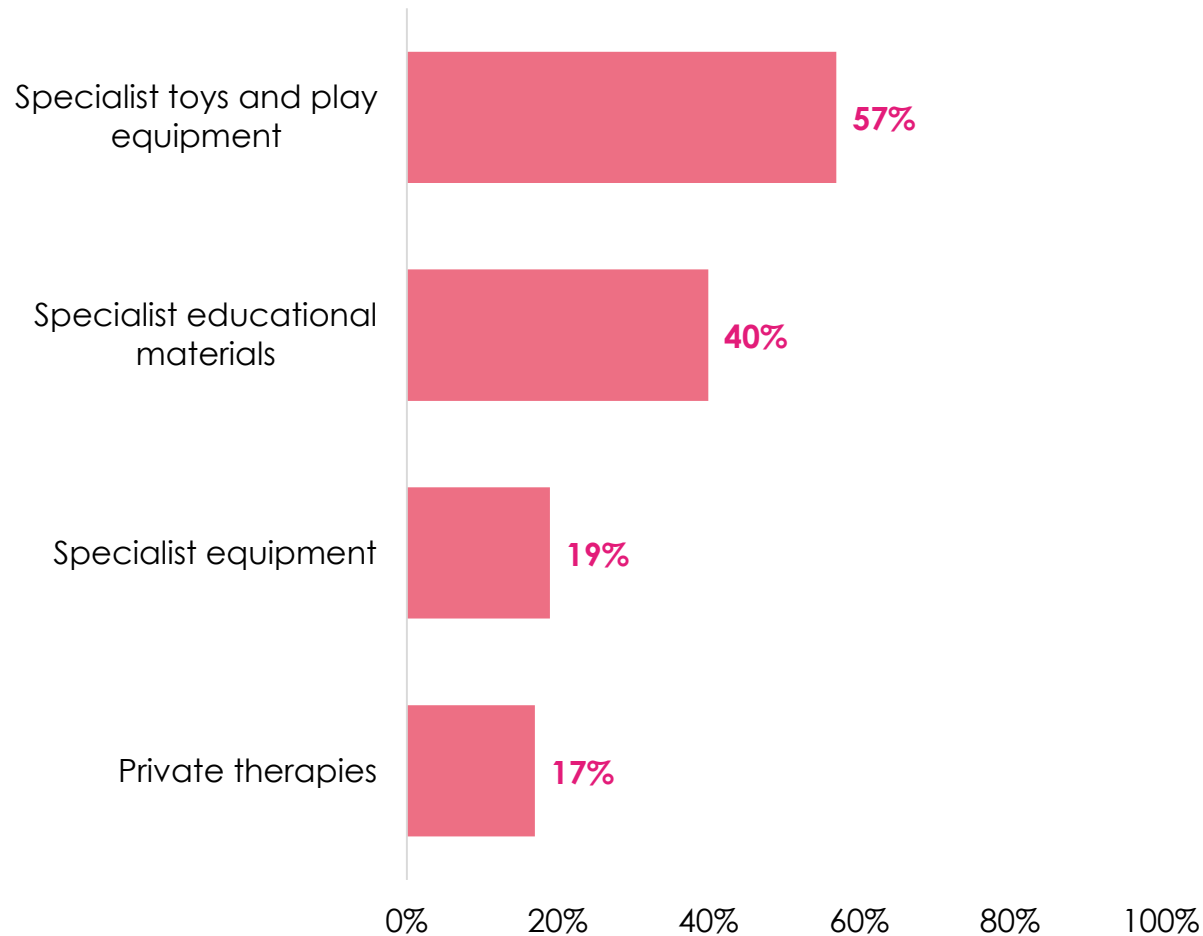
Many families raising disabled children not only face an income penalty, they also face extra costs as a direct result of their children's conditions and illnesses.

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# Increased and extra costs

Which of the following specialist items and services, have you had to buy without any financial support, as a result of your disabled children's conditions or illnesses? (n=1,055)



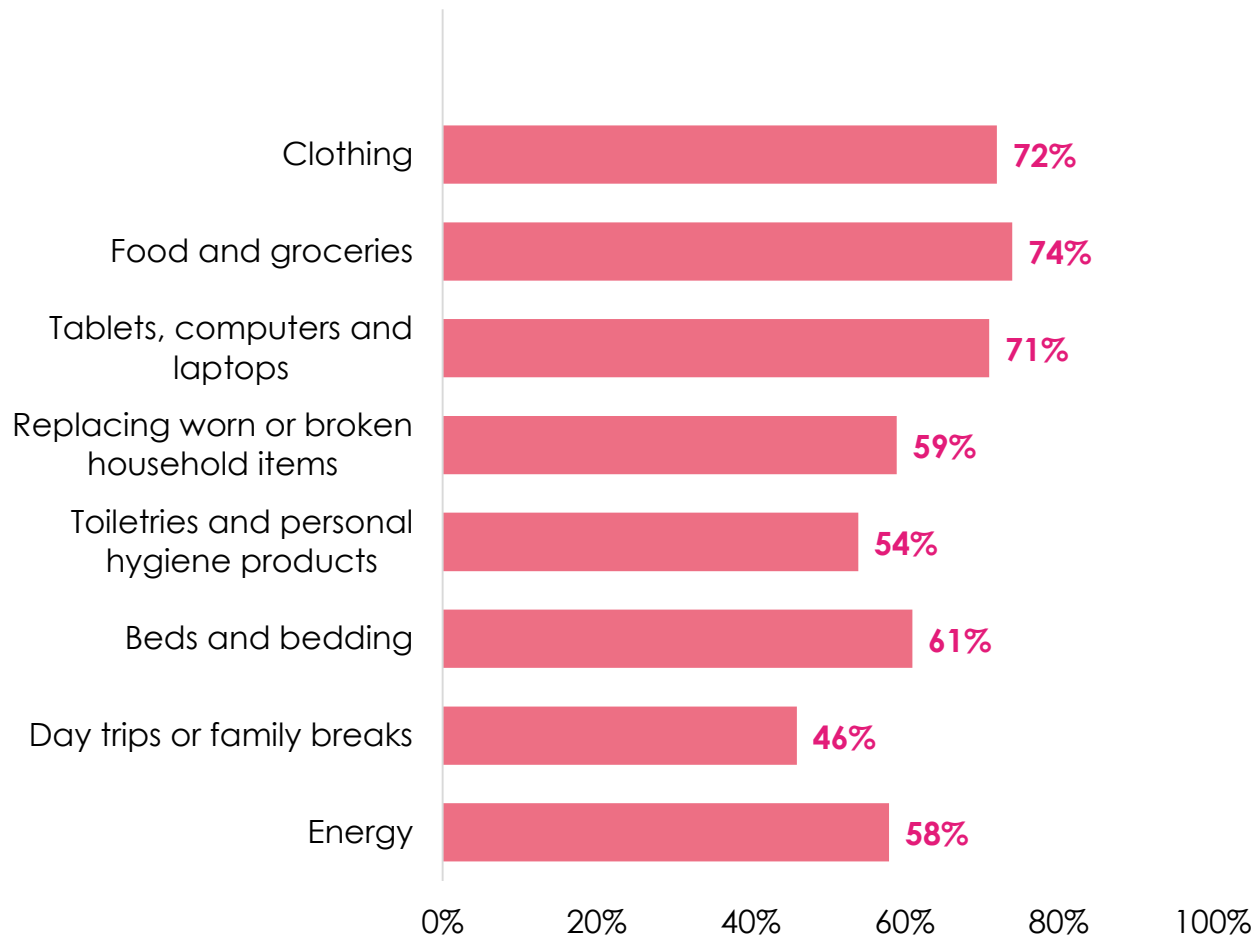
**72%**  
families report **having to buy at least one specialist item without additional support**





# Increased and extra costs

Which of the following regular household costs, do you have to pay more for as a direct result of your disabled children's conditions or illnesses? (n=1,055)



96%

families have to spend more on at least one regular household cost as a result of their child's disability



# Family's experiences of needing to spend more

*"Ava\* is 24/7 days a week care. We have someone with her at all times. Lights, tv, washing machine, tumble dryer and oxygen machines going all day and Night. We also have to keep our heating on 24/7 to keep our house's heating regulated so Ava is not going from warm to cold all the time causing her head colds etc"*

*\*Name changed*

*"My child only sleeps an average of 2-3 hrs per night and often goes 72 hrs with no sleep at all. As a result of this we use electricity all throughout the night. He also has sensory lights plugged in all day and night. He also has no awareness of keeping covers on and pyjamas etc, which means we have to use the heating more"*

*"My Son has several physical conditions made worse by the cold. Lights always have to be on as we are up through the night and he hates the dark. Sensory and calming toys and lights, washing machine and dryer on daily"*

*"We have to have at least 5 loads of washing a day due to bowel issues that my son has been waiting for to be fixed for nearly 7 years. We are hoping that this gets done this year as they have agreed he needs a stoma. Trying to dry the clothes is a nightmare. And we don't have the dryer on, but we are already at 600 with discount a month. It's scary times."*

*"He has muscle issues and cold effects him causing, pains, stiffness and shivering which can cause sickness and more. So I must keep him warm or risk him getting ill and going back to hospital"*



# Family's experiences of needing to spend more

Food allergies/ ARFID\* means I can't buy cheaper brands/offers as he wouldn't eat them. His extremely limited palate means I often travel between different shops searching for the things he will eat. I can't use free school meals for same reason so have to pay for own packed lunches

\*Avoidant/restrictive food intake disorder

My child requires a high calorie diet as her heart needs lots of extra calories just to function well, never mind to maintain normal growth. Unfortunately higher calories generally equal higher cost, things that are full fat are often considered 'luxury' items.

"My child has a very strict diet due to his sensory processing disorder and will only eat one colour food and only certain textures and flavour"

"My eldest son, Alfie\*, has had physical disabilities from walking and due to different physio treatments operations etc he is very tall, big build, muscles plus needs a low calorie healthy diet as he uses food when he is having severe panic/anxiety attacks. My youngest son, Ethan\*, is medicated for ADHD and the meds cause appetite loss over 12 hours so needs a high calorie diet. This is very expensive especially with cost of living so high"

\*Names changed

"My son is sensitive to gluten, allergic to milk and salmon. Gluten free and milk free is more expensive than normal food. Before when energy prices were normal I cooked lots, including bread, now I just do not have money for using my oven"



## The financial cost of caring

# 5. Benefits

The vast majority of families have to rely on state benefits for at least some of their income.

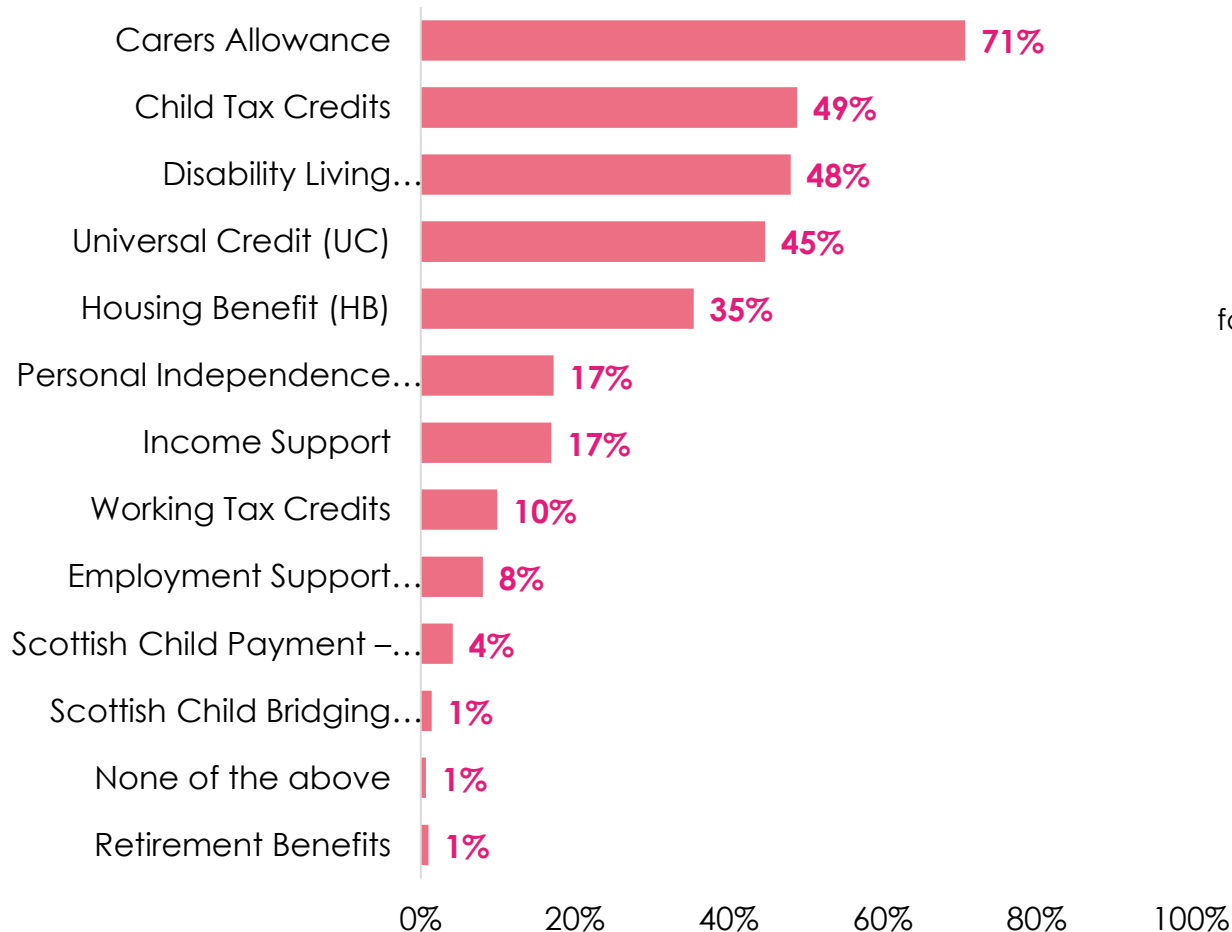
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# Benefits families receive

Which benefits do any of the adults in your household receive? (N= 1055)



89%

families report that their child receives disability benefits

<1%

families report that adults in their household do not receive benefits

23%

families report that their income is lower than a year ago



# Family's experiences of benefits

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“I’m so grateful for the help we get so I can stay home to care for them. Benefits, grants, support from social work, I am so grateful for it all”

“If I could change something it would be the government plans to how its affecting everyone. It’s so unfair to have these pressures on life when it could be easily controlled and more help could be available to everyone in need”



## The financial cost of caring

# 6.The cost of living

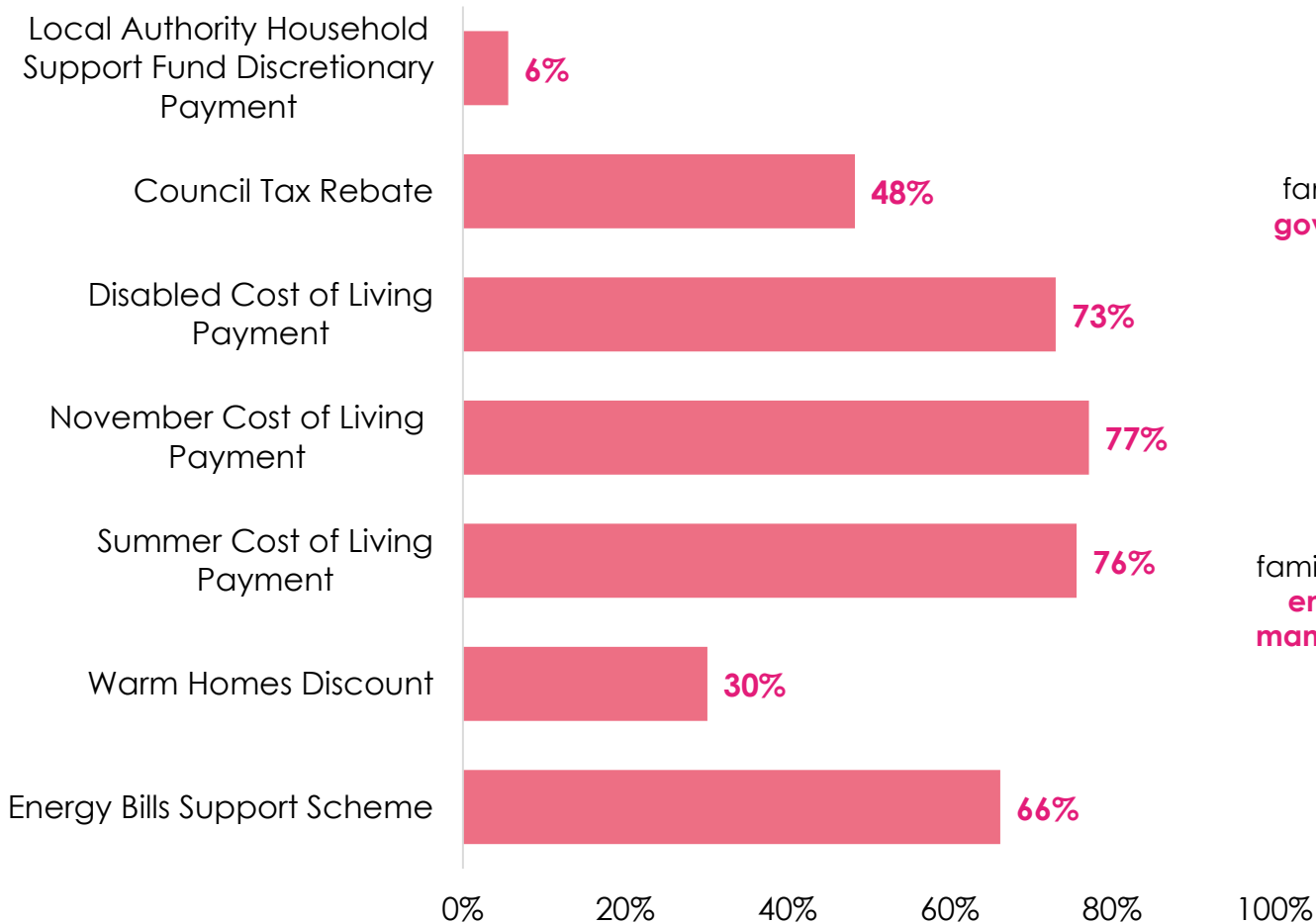
The increased cost of living has been a huge concern for families in preceding Family Polls. We asked families if they felt that Government cost of living help was enough

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# Government cost of living support

What Cost of Living Support has your household received in 2022? (n=1,055)



93%

families report **receiving government cost of living support**

50%

families feel **this support has enabled them to better manage** the increased cost of living



## The financial cost of caring

### 7. Savings

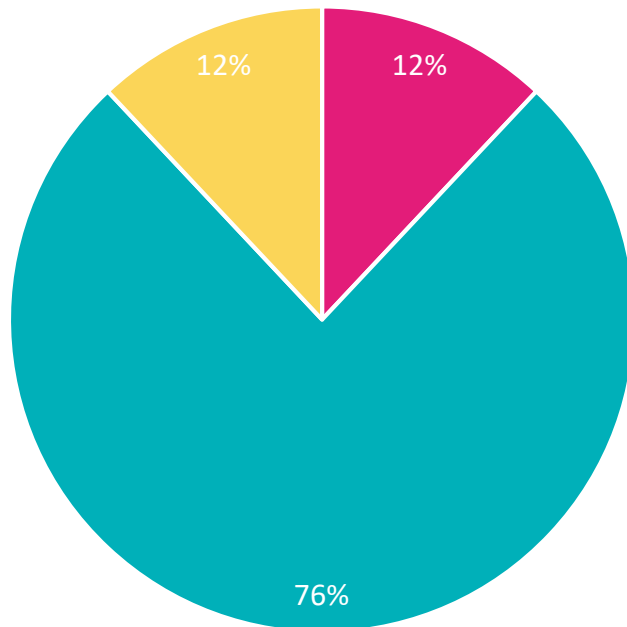
Families are in a financially precarious position with many having very limited access to savings and relatively small unforeseen costs being enough to cause significant financial distress

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# Family savings

Would your household be able to pay an unexpected expense of £200? (n=1,055)



■ Yes ■ No ■ I don't know

$\frac{8}{10}$

families report **that they have no savings**

$\frac{1}{4}$

families report **that their savings are lower than a year ago**

$\frac{7}{10}$

families report **that they are unable to save £10 a month**



The resulting financial difficulties

## 8. Falling behind

As a result of the financial challenges that families raising disabled children face, many struggle to cover their everyday costs and bills.

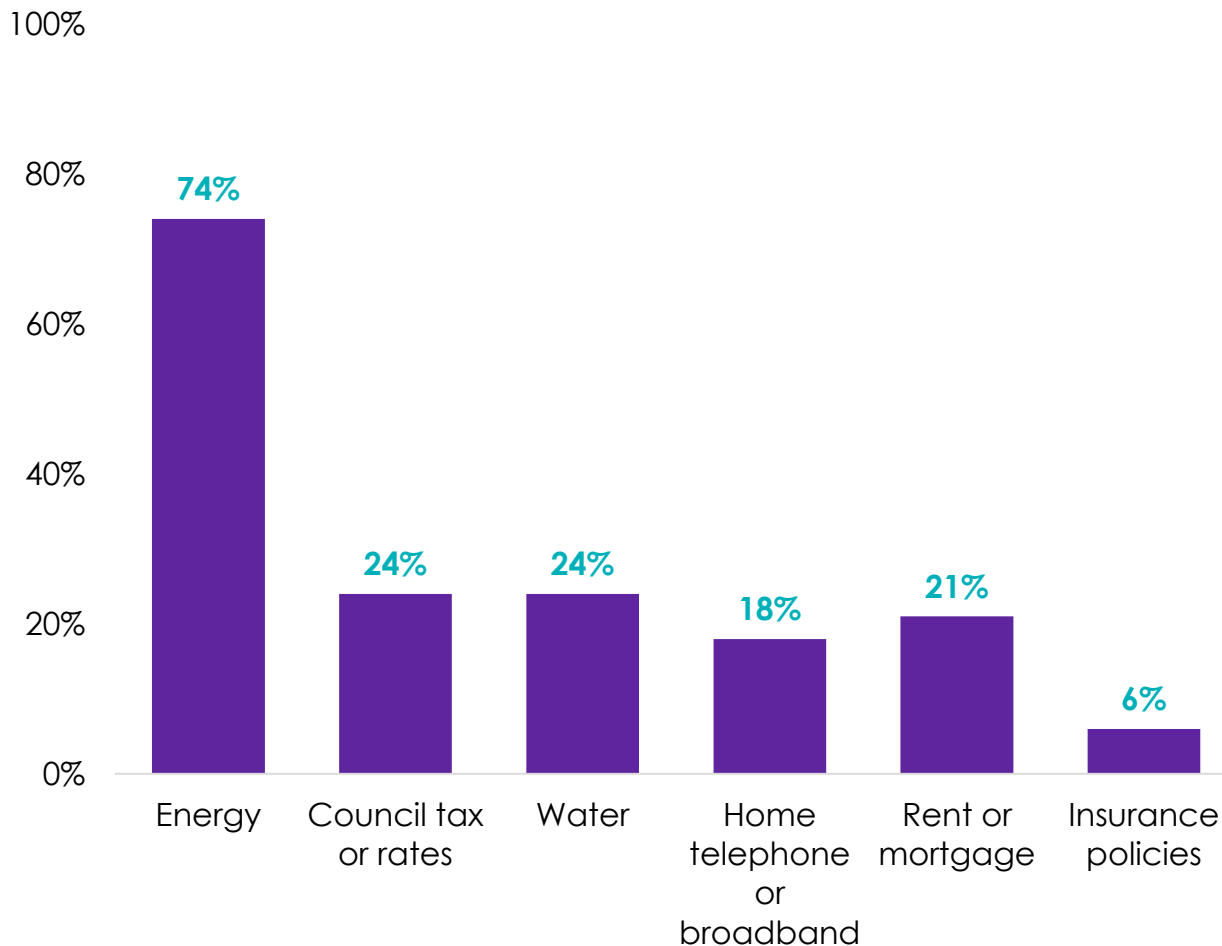
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# Falling behind

Which regular household bills are you currently struggling with or falling behind on? (n=936)



9 / 10  
families report that their household bills have increased over the last 12 months

9 / 10  
families report struggling or falling behind on their household bills.



# Family's experiences of falling behind

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*"Everything has gone up. I get paid and then each time I check, my bank the balance has gone down by so much so quickly, I am in a constant state. I'd worry about making my rent payment. Prices continue to rise which is so worrying"*

*"Having to explain to my son why he can't buy lunch as usual or that he needs to take a packed lunch and setting limits on it that aren't enough to get him his usual meals. Or why there is less food or less healthy foods in the house. Or that he will need to wrap up as I can't afford the cost of heating or not have his electronic devices on as usual. Or reduce his shower time"*

*"Buying less food and paying bills late so I can put majority of money on gas, electric"*

*"Keeping warm and food, as we cannot always do both"*



The resulting financial difficulties

## 9. Going into debt

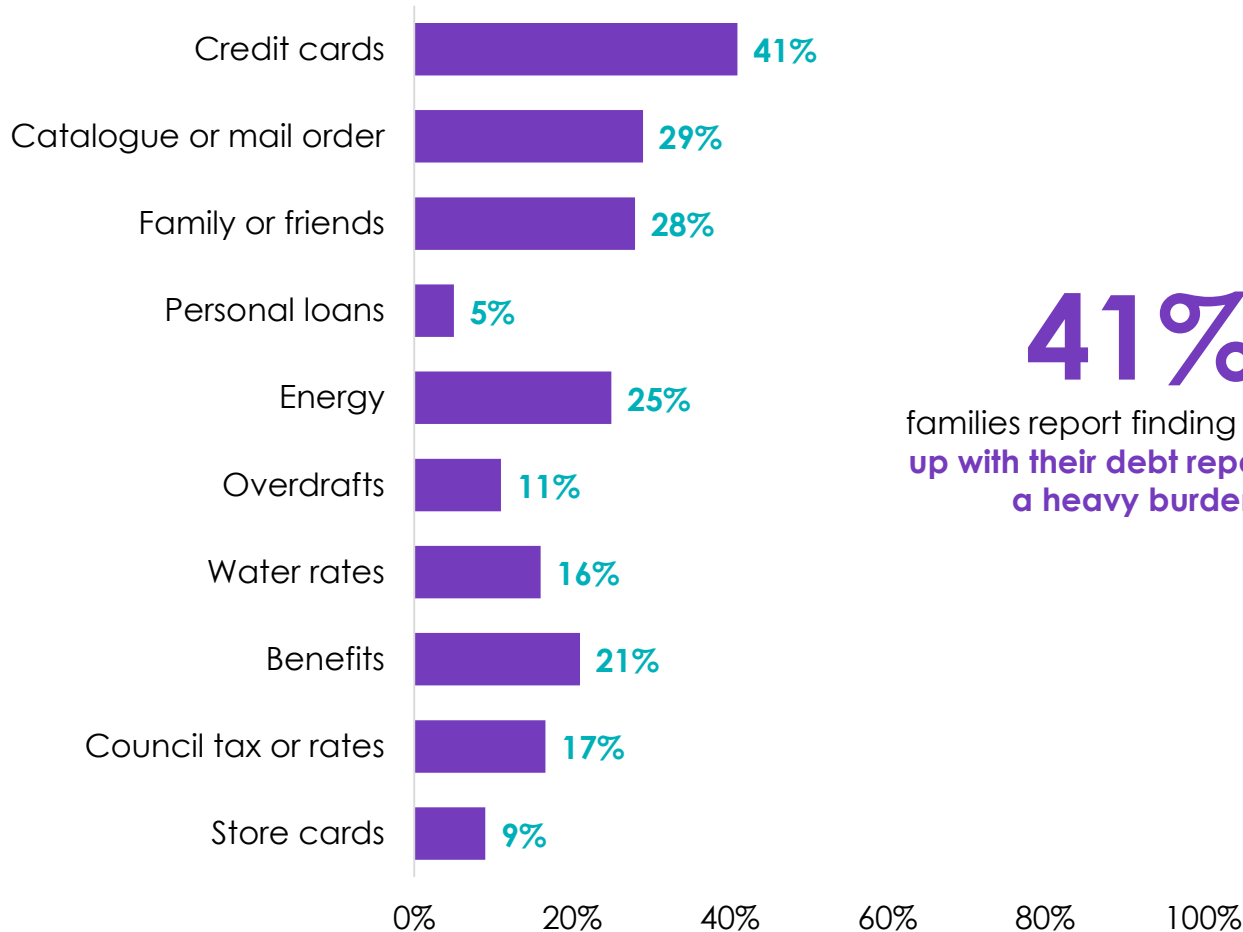
Where families cannot make any further cut backs, they are often forced to go into debt to pay for essential items and bills.

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# Going into debt

Which debts does your household currently have? (n=1,055)



56%

families report their **debts have increased** in the past year

41%

families report finding **keeping up with their debt repayments a heavy burden.**

28%

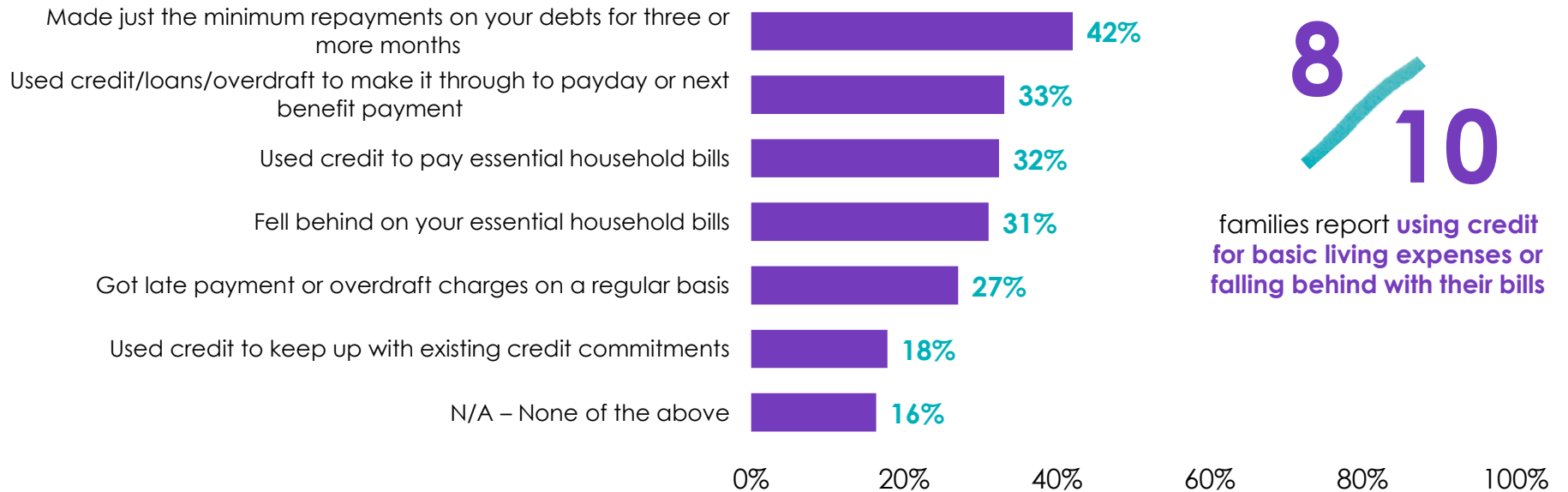
families **think they will need to go into further debt** in the next six months.



# Trying to financially cope

Which, if any, of the following have you done in the past 12 months?

(n=1,026)



# Family's experiences of going into debt

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*"Very tough.. Just have nothing left each month and getting into debt because of the cost of living"*

*"Everything has gone up in price and I'm now in debt and I've never been in debt before"*

*"Debts, and worry how to keep food on the table and the house warm"*

*"We are trying to manage our debt so we have minimal interest and charges. Hopefully in time our finances will balance out when we can work more reliably"*



The resulting financial difficulties

## 10. Going without

In many cases, families raising disabled children are forced to make sacrifices, and go without things others take for granted, because of financial difficulties.

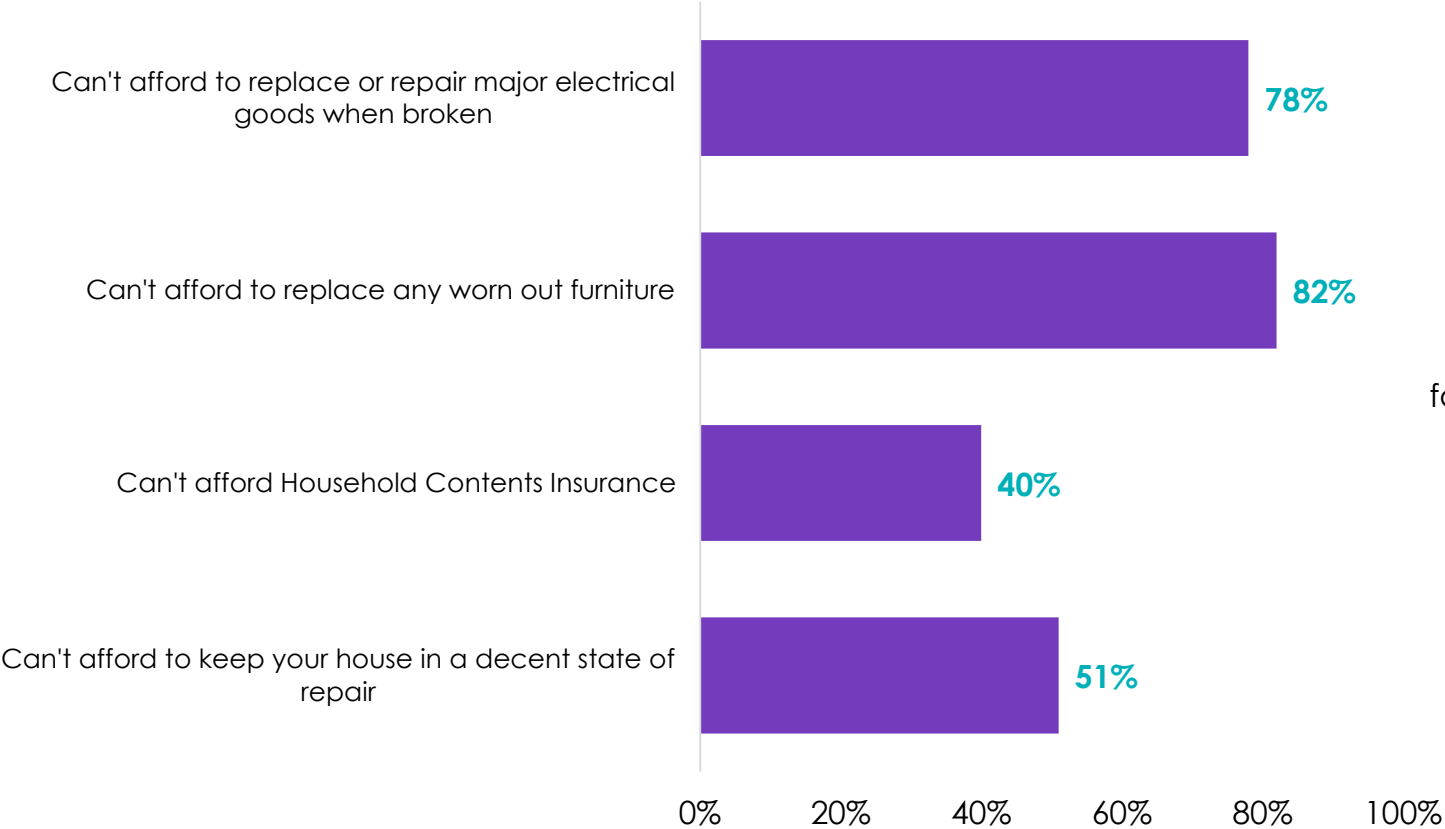
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# Going without as a household

What does your household need but had to go without? (n=1,055)



1/2

families cannot afford to keep their home warm enough



# Family's experiences of their household going without

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*"I'm on a pay as you go meter and spent 60 pound in a week on gas and it was still gone by Sunday morning, so couldn't have any heating until my carers allowance went in on the Monday. How we're getting through Christmas..."*

*"Going without food, heating etc. Being unable to fully provide for my children"*

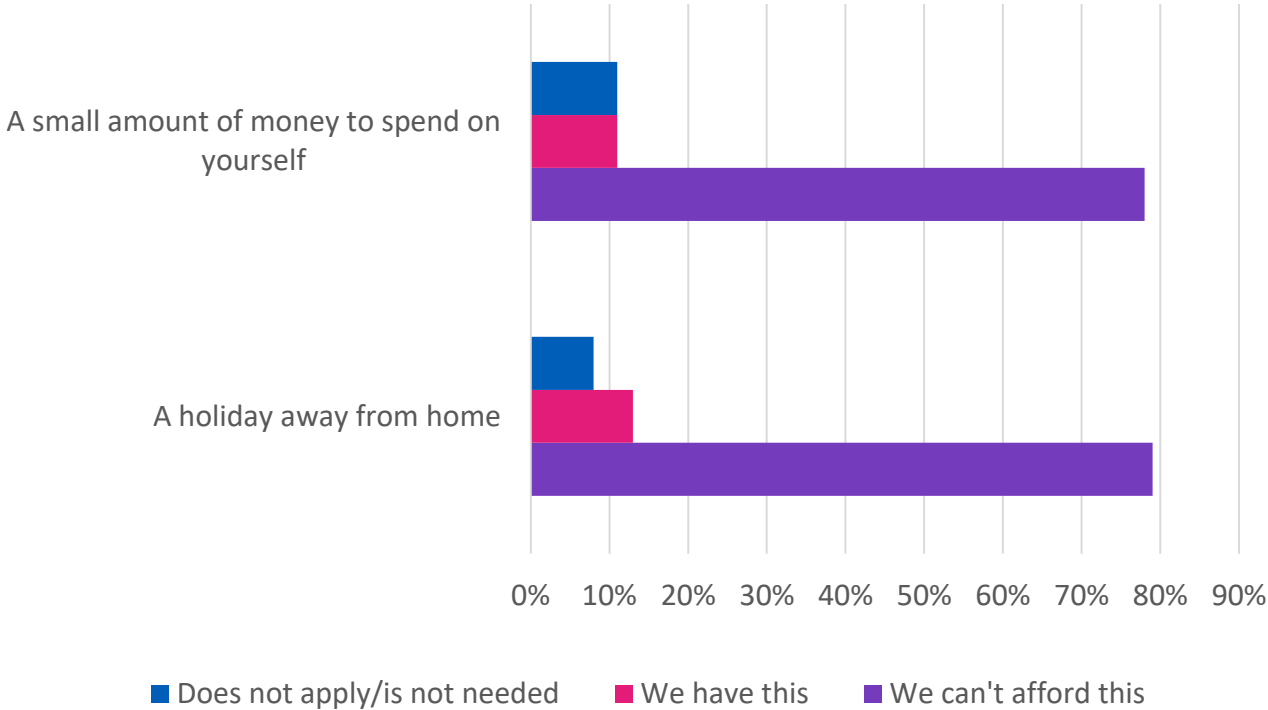
*"Cutting down on heating home, wearing more clothes"*

*"Rationing heat. It's snowing here at the moment and we can't afford to turn the heating on"*



# Parents and carers going without

What do adults in the household need but have to go without?  
(n=1,055)



3/10

families had used a foodbank in the last 12 months

4/10

families were experiencing very low food security



# Parent's and carers experiences of going without

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*"It sometimes my child eats before I would eat just to make sure they're full up before I even try food"*

*"I go without meals so the kids have plenty"*

*"Just trying to get by using food banks when needed".*

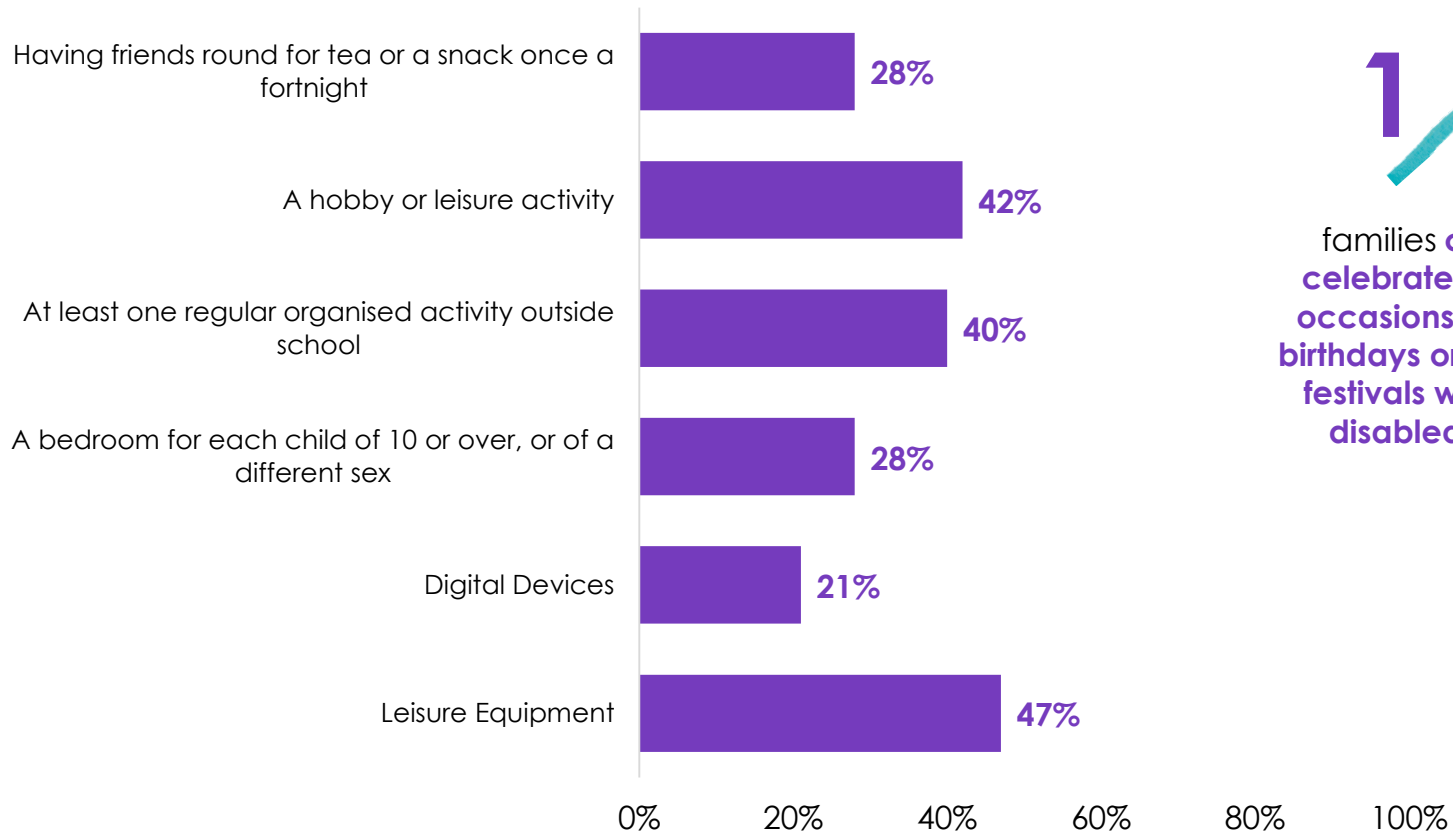
*"Just trying to keep us afloat and our heads above water. The vouchers and food hampers we received from school have helped".*

*"I'm walking round in clothes with holes due to putting the children first".*



# Children going without

**What do you need for your disabled child but are unable to afford?  
(n=1,055)**



**1/4**  
families **cannot**  
celebrate special  
occasions such as  
birthdays or religious  
festivals with their  
disabled child



# Children's experiences of going without

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*"My children miss out on so many things because I cannot afford them.... They have never even been to see Santa because I can't afford to pay for them... Or swimming because I cannot afford it"*

*We don't do family things i.e. cinemas anymore. We don't do days out full stop other than to the park, but it's now too cold.*

*"...child's birthday in December, then Christmas. He believes in Santa and doesn't understand why Santa cannot give him gifts"*

*"We have to cut back on things and outings that we used to enjoy as a family"*



The resulting  
wellbeing impacts

## **11. Disabled children**

The situation families find themselves in has a negative impact on the health, wellbeing and quality of life of disabled children.

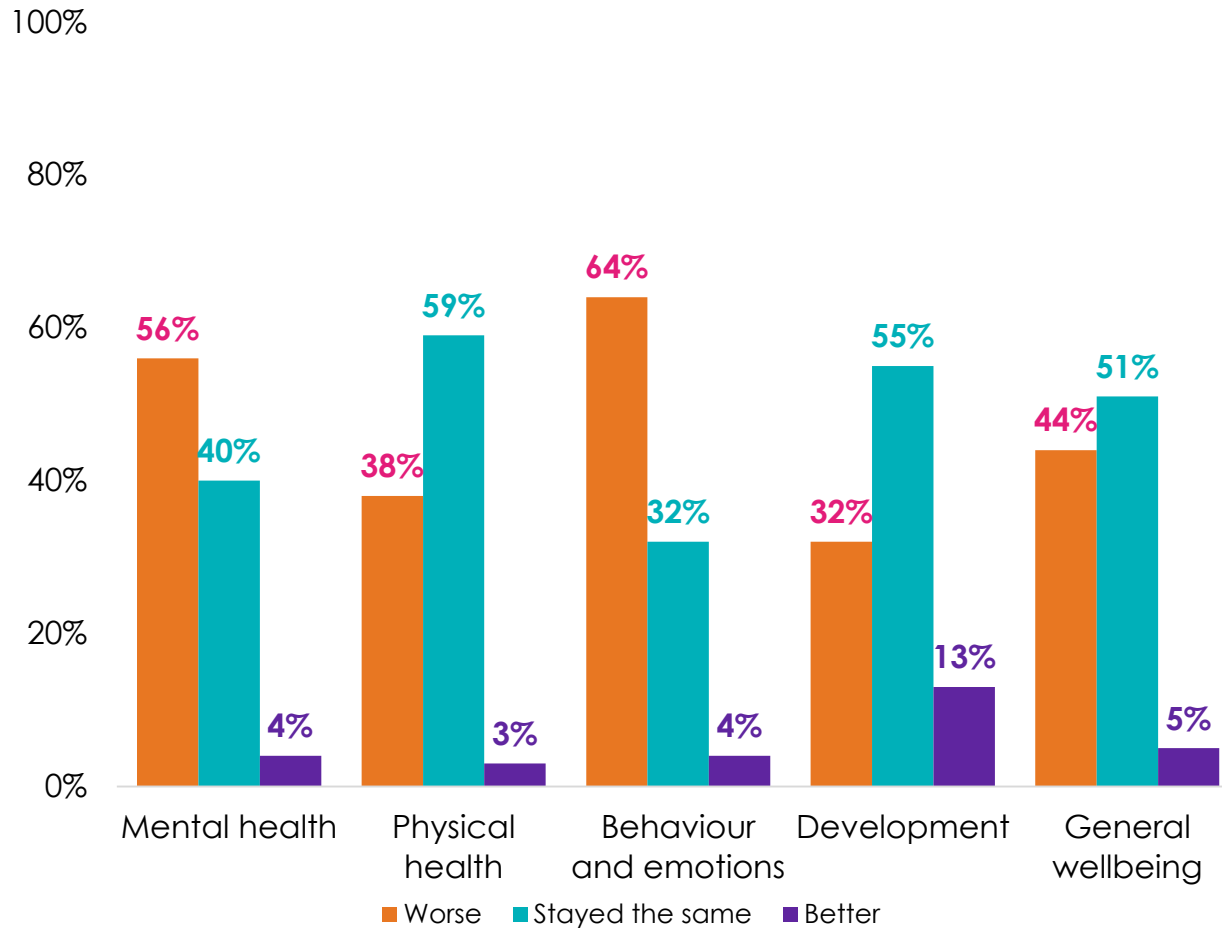
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# Impact on disabled children

How would you say the following have changed for your disabled children over the past 12 months? (n=1,055)



## 74%

families report that some aspect of their disabled child's health, development or well-being have deteriorated in the last 12 months



The resulting  
wellbeing impacts

## **12. Non- Disabled children**

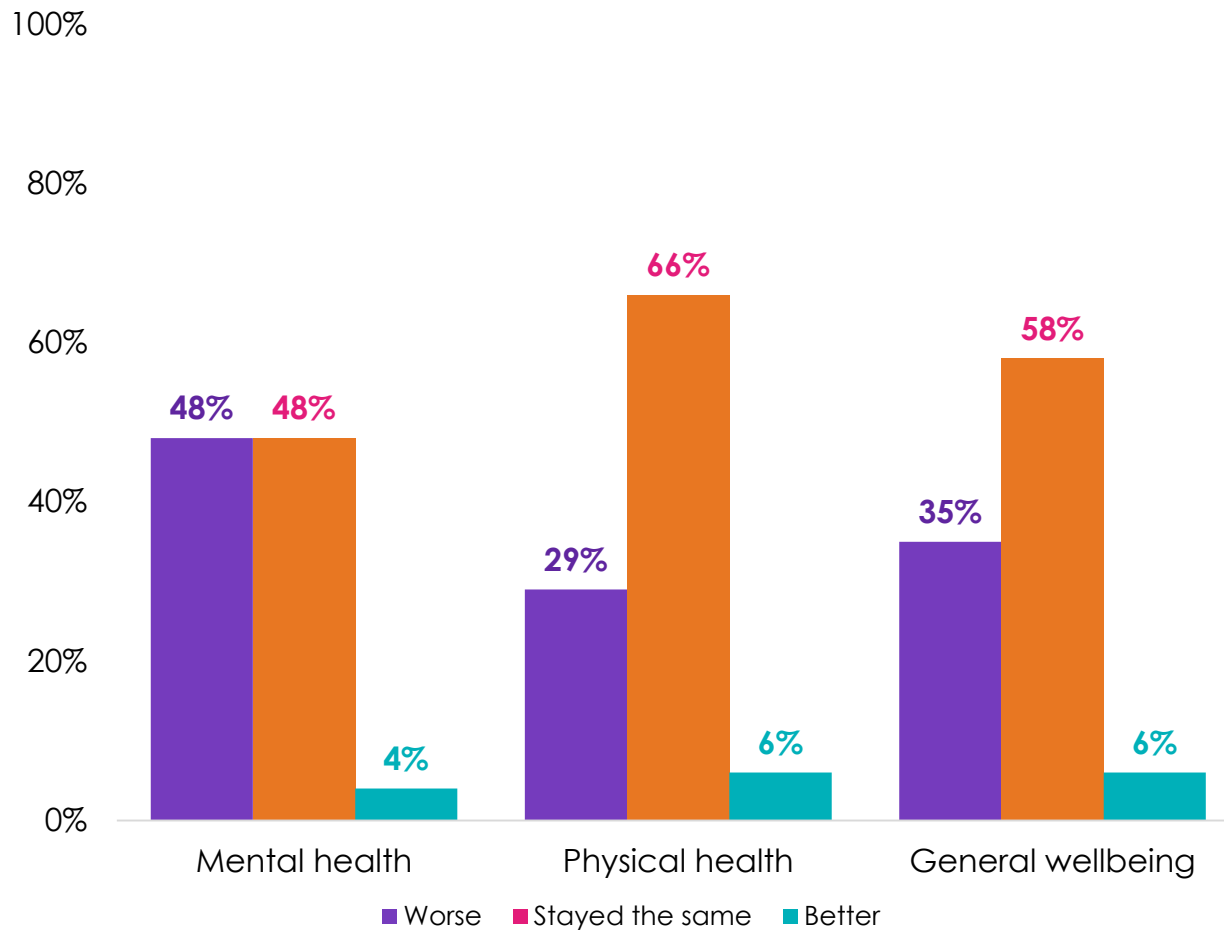
The health and wellbeing of many non-disabled children has also been negatively affected.

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# Impact on non-disabled children

How would you say the following have changed for your non-disabled children over the past 12 months? (n=661)



1/2

Of families felt that their **non-disabled children's health and well-being had declined** in some way over the last 12 months



The resulting  
wellbeing impacts

## 13. Parents and carers

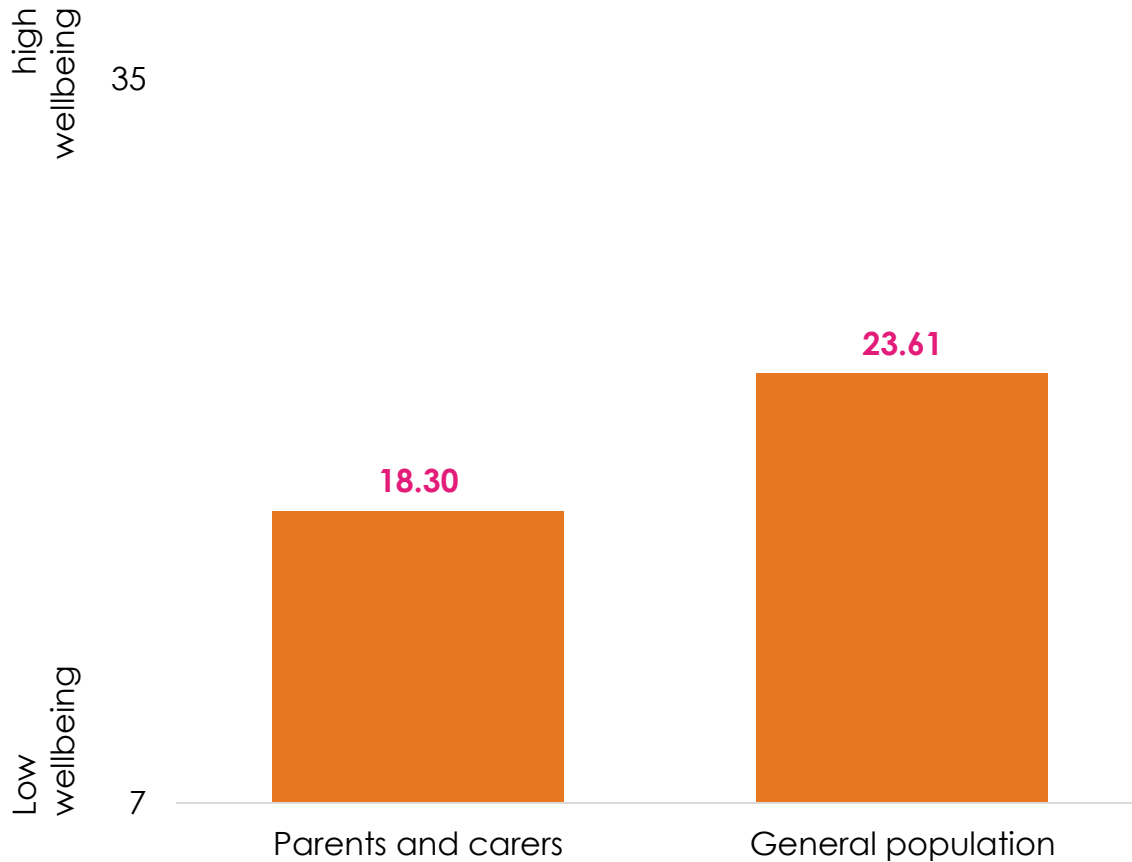
The health and wellbeing of  
many carers has also been  
negatively affected.

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# Impact on parents and carers

Wellbeing score (Short Warwick-Edinburgh Mental Wellbeing Scale) (n=1,055)



1/4

parents and carers report the highest possible **loneliness** scores



# Parent's experiences of the impact of caring

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*"I can't afford to have any time for myself either, and I've become very lonely and isolated, I don't feel like I can talk about this to anyone as I keep such a brave face on, I don't want to worry people. Life is very hard at the minute"*

*"It's very challenging, especially a single parent. No help somewhere else. I feel left out"*

*"My life has been on hold for 16 years. Along the journey fighting to meet or ensure her health and education needs has stripped everything meaningful in my life. This affects my self esteem"*

*"Being very unwell physically, and emotionally the past 2 years. It has been a real struggle .. and I feel mentally drained"*



# Parent's experiences of the impact of caring

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*"Am I sad? I think I'm falling at times cos of the cost of living and it's got a massive hold on us, yes. Has my mental health been affected? Yes."*

*"Mentally I have been overwhelmed most of the time. I'm a single mother and I'm the only one who looks after him. Is not easy to find time for myself. "*

*"I am struggling, I am stressed, I am worried, crying again and again, but I am not letting my feelings to affect my child. So.....positive or negative we have to go forward"*

*"How lonely it really is. You discover emotions you didn't even no you had. My mental health is so low coz you take your self away from The world"*





# Parent's experiences of the impact of caring

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*"I'm a single adult with an ASD child. Even her school didn't quite understand how, while my daughter was in isolation, I couldn't go out to shops etc. They couldn't quite understand that I am very isolated and have no family support (family lives 40minutes away, are elderly and vulnerable themselves, and are somewhat apprehensive of my daughter and her behaviour). So, a lack of understanding, not of my daughter's ASD itself, but of our situation"*

*"It as been do difficult as I had a bleed on the brain and I am very poorly and looking after my daughter and 3 children the best I can"*

*"its hard work especially as I myself am registered as disabled and there doesn't seem to be enough help out there when one parent is disabled, the other a full time carer of us all"*

*"My anxiety and epilepsy have been deeply affected and I have been isolated due to inability and costs of getting carers. Also lack of support from family and friends"*





## Contact us

If you are interested in finding out more about this research or sharing the findings, please get in touch with either our research or partnership teams:

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# Family Fund

**Helping disabled children**

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