

"Struggling to
survive since
everything
has gone up."



The Cost of Caring

A report exploring the challenges facing families
raising disabled children

October 2022



Family Fund

Helping disabled children

Cost of caring

A report exploring the challenges facing families raising disabled children



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Introduction

About us

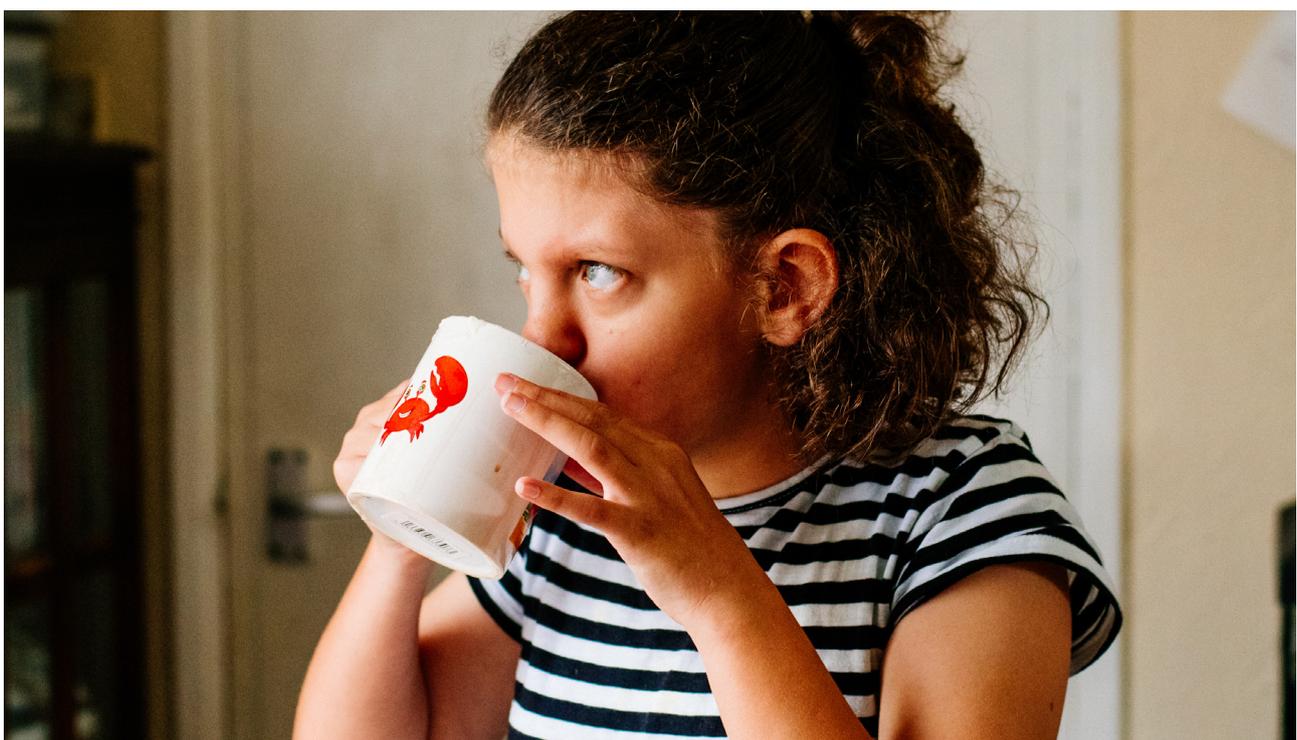
Family Fund is the UK's largest charity providing grants for families raising disabled, or seriously ill, children and young people.



Last year we delivered over 150,000 grants and services worth over £32.3 million with the support of the four UK Governments, charitable trusts, trading income and donations.

We believe all families raising disabled, or seriously ill, children should have the same choices, quality of life, opportunities and aspirations as other families. Focusing particularly on families raising disabled children on low incomes, we aim to make a real difference in their lives.

We provide grants for essential items such as kitchen appliances, sensory toys, family breaks, bedding, tablets/computers, furniture and clothing. We also provide information and support for families that apply to us, in order to help them access further relevant support.



Foreword

This past year has been incredibly challenging for many, but even more so for families on low incomes raising disabled, or seriously ill, children. The coronavirus pandemic is still having a disproportionate and negative effect on everyday lives, and on top of this, families are now facing a cost-of-living crisis, with increasing costs for all their basic needs such as higher energy bills and everyday household costs. As a result, many families are plunged into debt and are finding it almost impossible to make ends meet.

This means the support we provide to families has never been as important as it is today, and the research we are presenting highlights exactly that - the positive difference Family Fund makes to their lives. Whether it's an iPad to support communication at home or connecting with family members living far away, a fridge that allows medication to be stored safely or is large enough to reduce trips to the supermarket, or a much-needed

break to enjoy some fun and quality time together, our grants support the family as a whole - improving wellbeing and quality of life and easing the additional daily pressures many families face.

Our research shows that the outlook for many of our families is extremely grave. The time that parents and carers need to spend supporting and caring for their disabled children means that many are unable to increase their income to meet spiralling costs. We therefore need to work together with partners from across the public, private and voluntary sector to go further in ensuring no families raising disabled children are forced to go without.



Cheryl Ward
Chief Executive, Family Fund

Methodology

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

The sample size for each quarterly poll is 1,066 families raising disabled children. This report brings together results from polls that took place in September 2021, December 2021, March 2022 and June 2022. In total across the four polls, the research has engaged 4,264 families, with 6,994 adults, raising 6,074 disabled children and 4,372 non-disabled children.

A sampling approach was applied in this research to ensure the results were broadly representative of families on low-incomes raising disabled children living across the UK. Sampling was applied on the following characteristics; geography, disabled children's age, and disabled children's gender.

To help mitigate the impact of Family Fund grants on the responses given, all families surveyed for the poll had not received a grant from Family Fund within the previous six months.

Thanks to all families who shared their stories

Thank you to all families across the UK who gave up their valuable time to share their views, opinions and experiences with us. We are incredibly grateful to every family that took part in a poll. Without their contribution, this report would not have been possible.



"I've **stopped eating breakfast,** and rarely eat lunch, as I try to make sure my kids have everything they need."

Parent, West Midlands

Executive summary

“The cost of living [is] going up much faster than my income and [I am not] able to earn more as my son needs 24/7 round-the-clock care.”

Parent, Wales

The families that we support have shared with us “The Cost of Caring” and the daunting challenges they now face.

This report shows how families with disabled children, struggling to recover from the pandemic, must now grapple with a cost-of-living crisis which places the vast majority in acute financial jeopardy. As families with disabled children have higher costs and are able to work less, their financial challenges have become largely insurmountable. Many are now at acute risk of experiencing poverty.

Price rises across the board, particularly in relation to food and energy, have pushed families to their very limits and this is likely to worsen in the year ahead. The time that parents and carers need to spend supporting and caring for their disabled children means that many are unable to increase their income to meet spiralling costs. “The Cost of Caring” shows the stark choices facing families, as many are forced to forego even the essentials of living- food; heating and basic furniture such as beds or flooring, washing machines and fridges in order to make ends meet.

The report is based on information provided in the charity’s last four quarterly family polls from September 2021 to June 2022. It shows that on average parents and carers spend 60 hours a week providing help and looking after their disabled children and one third spend more than 100 hours. By contrast they receive an average of only one hour a week of respite and support.

As a result less than one in four parents and carers are able to work full time and over half do not work at all and are dependent on grants and benefits.

As one carer stated:

“Caring for our child is not the issue, she is the light of our lives. Being able to access the right care, education and support in order to provide me the opportunity to work is key.”

Parent, North West England

On average, families raising disabled children live on £17,000 a year and report their income has decreased by £400 during the last 12 months. At the same time they face additional and escalating costs. Not only do they have to increasingly pay out for specialist items such as adaptations, sensory items and therapies but they have to pay more for clothing, food and household goods due to extra wear and tear or special dietary requirements.

Another parent stated:

“How will I be able keep my disabled child warm this coming winter when I'm struggling to pay gas and electric in summer? My disabled child needs to be warm for medical reasons. How will I afford petrol which I need as I have two children with physical disabilities including one in a wheelchair. And the cost of food, and availability of safe food for an autistic child if shortages start happening. I worry every day and night over this.”

Parent, West Midlands

In September 2021, families raising disabled children reported their household bills had increased by an average of £800 a year. By June 2022, this increase was more than £1,500.

- 54% of parents and carers report cutting back on the size of meals or skipping meals completely to provide enough food for their children;
- 40% of families report they can't afford to keep their accommodation warm - an increase of 13% since last December;
- Nine in 10 families raising disabled children (92%) say they are struggling or falling behind on their regular household bills;
- Four in five families are in debt and debt levels are rising for the majority.
- Many families worry about what the future holds and what they will be able to do to support their disabled children this winter, and beyond. Our research shows many feel isolated and their mental and physical health has worsened.

It is therefore critical that we work urgently with our government partners and others to help relieve these acute financial hardships.



Cost of caring - income and expenditure

Reduced incomes

For families raising disabled children, the ability of carers being able to work, maintain or increase their incomes, is significantly limited by the time they spend caring.

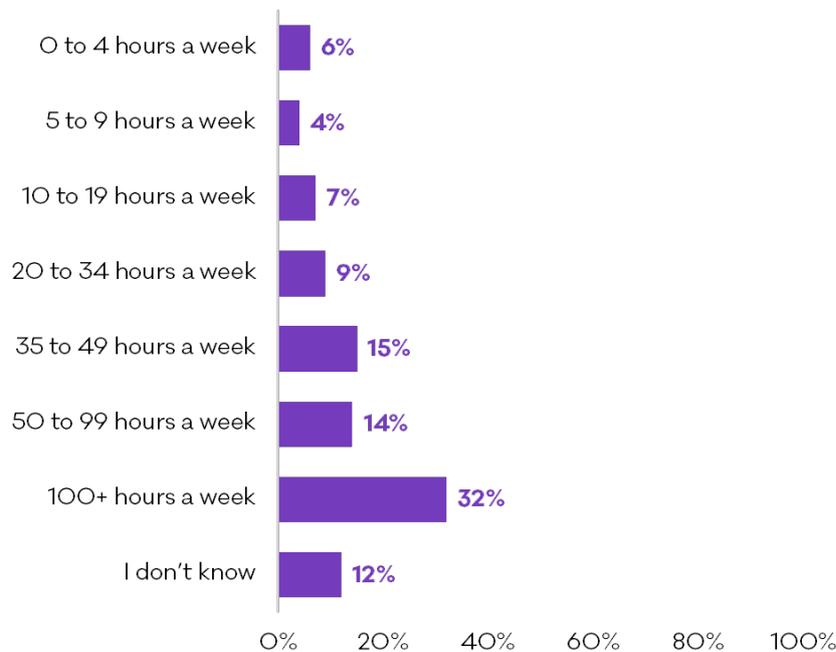
"I love my children to death but I get no time to myself apart from when they are in education. I would love local services to take me seriously and provide respite as I have no family, no friends and am incredibly isolated. I have no time to myself at all and as much as I love my children, I feel so isolated, lonely and suffocated."

Parent, East England

- On average parents and carers spend around 60 hours a week providing help and looking after their disabled children, with a third (32%) caring for more than 100 hours a week;
- More than two in three parents and carers (69%) report that they are unable to work at all or as much as they would like to;
- Less than one in four adults (23%) in families work full time;
- Up to 59% of adults currently report that they are not working;
- In almost half of cases (47%) there are no adults in employment within the household.

These numbers have changed little since before the pandemic, despite declining levels of unemployment in the wider population across the UK.

About how many hours a week, on average, do you spend providing care and help for your disabled children? (n=1,066)



"I've gone from working full-time to now unemployed, and isolated as I have no support with respite or childcare due to my son's behaviour. I can't get a worthy job that would work around the school hours. I feel life can feel so pointless at times."

Parent, East Midlands

The ability of adults with disabled children to work is limited by a lack of respite, care and support available to them. Just one in five families (21%) reported that their disabled children were cared for by others outside of an educational setting.

On average, families received just one hour a week of respite, care and support.

The pandemic has further limited the care and support available to families. Despite some recent improvement, two in five families (42%) report they are still receiving less financial support for their disabled children than before the beginning of the coronavirus pandemic, and the hours of respite, care and support being received by families remains largely unchanged. As a result, parents and carers of disabled children are more likely to need to rely on the social security system as a primary source of income. This means, on average, families raising disabled children live on £17,000 a year.

They report their income has decreased by £400 during the last 12 months.

Just one in ten (13%) have seen their income increase in the last year.

Increased and extra costs

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

Specialist costs

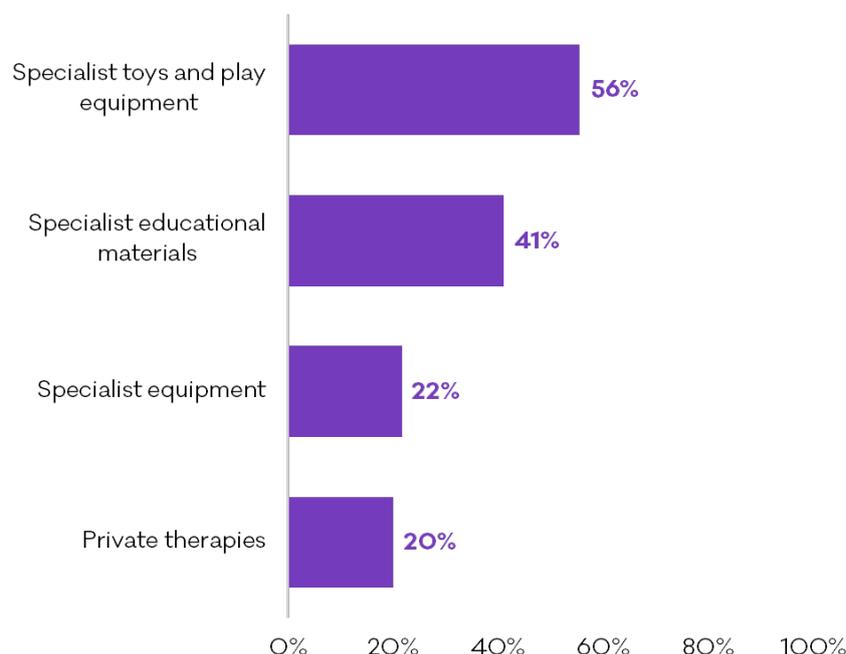
These are items which only families raising disabled children would need to pay for, such as sensory items, wheelchairs, home adaptations, therapies, and personal assistants and carers. In some cases, families raising disabled children will be able to receive financial support to help to purchase these specialist goods and services. However, our research indicates that many families are themselves having to find the money to buy these.

"Cost of equipment that should be provided by the NHS, such as a specialist buggy that cost £1,000, was offered as a NHS voucher for £189."

Parent, North East England

- Three in four families raising disabled children (76%) report having to buy some form of specialist goods and services without any financial support;
- The most common specialist costs families have had to pay for include specialist toys and play items (56%); specialist educational materials (41%) and specialist equipment (22%) related to their children's conditions or illnesses.

As a result of your disabled children's conditions or illnesses, have you had to buy any of the following specialist items and services without financial support? (n=1,066)



Regular costs

Families raising disabled children also have to spend more on regular costs. This may be because they need to use more of an item, experience greater wear and tear so have to replace items more regularly, or have to buy more expensive types, and brands of, goods or services due to their disabled children's conditions or illnesses.

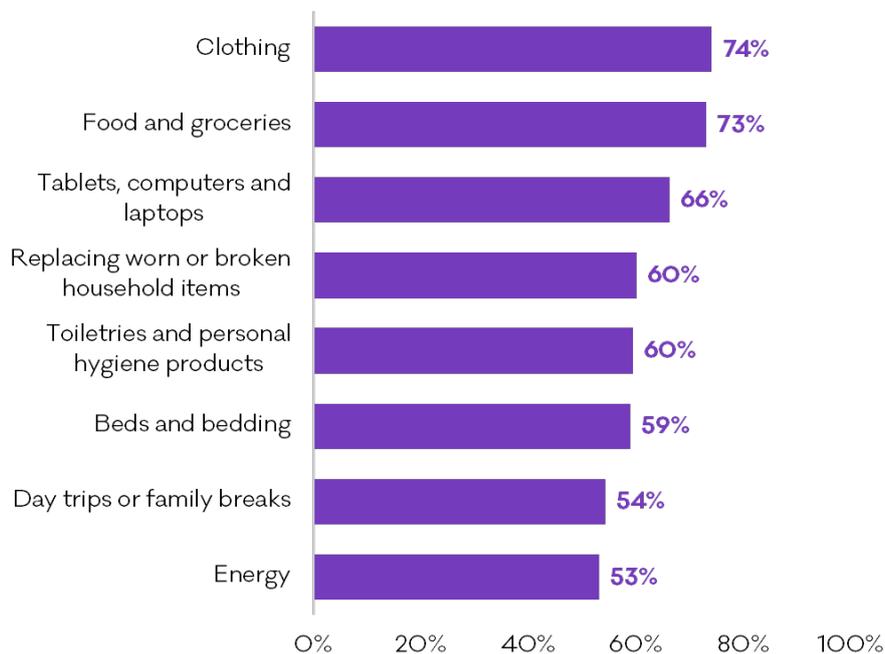
“My child who has ADHD gets into anger issues and smashes things and can't have medication due to epilepsy. Also she has OCD and washes and showers around 3 to 4 times a day, so the wear and tear and energy bills are around £60 to £70 per week and gas around £50.”

Parent, North West England

Almost all families raising disabled children (98%) reported paying out more on regular costs than families with non-disabled children, and these cover a wide range of areas:

- Clothing (74%)
- Food and groceries (73%)
- Technology such as tablets (66%)
- Toiletries and hygiene products (60%)
- Replacing worn or broken household items (60%)

As a result of your disabled children's conditions or illnesses, do you have to pay more for any of the following household costs? (n=1,066)



Not only do the families that Family Fund supports have to cope with decreasing incomes and additional costs, but the current cost-of-living crisis means their additional costs are rapidly increasing. These increases can be seen across all the regular household bills that families raising disabled children need to pay for, but predominantly in energy and food costs. As high as 96% of families raising disabled children report that their energy costs have increased in the last year, and 93% report that the cost of their weekly food shop has increased.

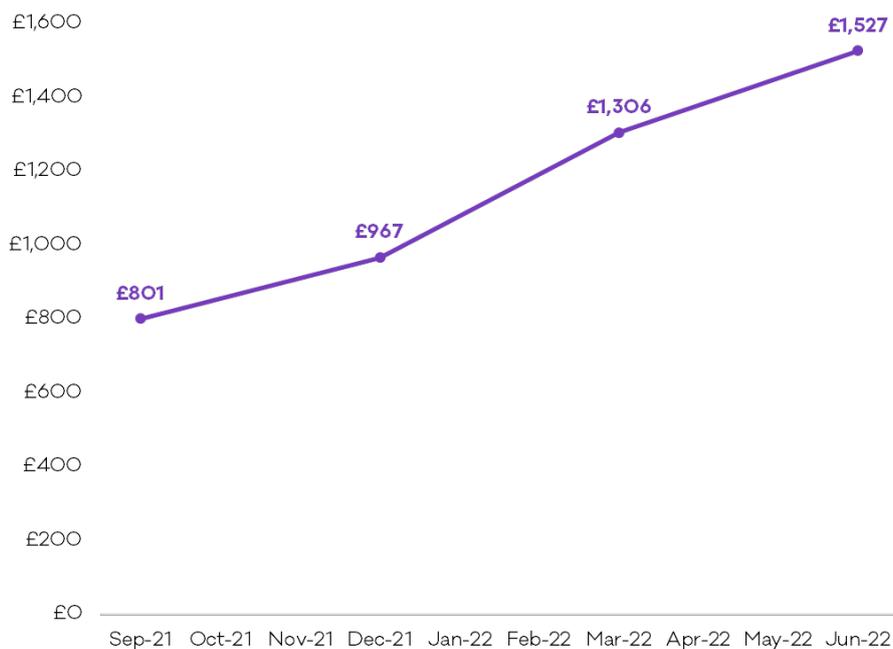
“Struggling to survive since everything has gone up. Food is a struggle as I can only spend what I used to spend but get less. Electricity has gone from £20 a week to £60 to £70 a week. We are in the house all the time.”

Parent, Wales

In September 2021, families raising disabled children reported their household bills had increased by an average of £800 a year.

By June 2022, this increase was more than £1,500.

Thinking about how much higher/lower your current regular household bills are, compared to 12 months ago, which of the following describes the change? (n=1,066)



Financial difficulties

Falling behind

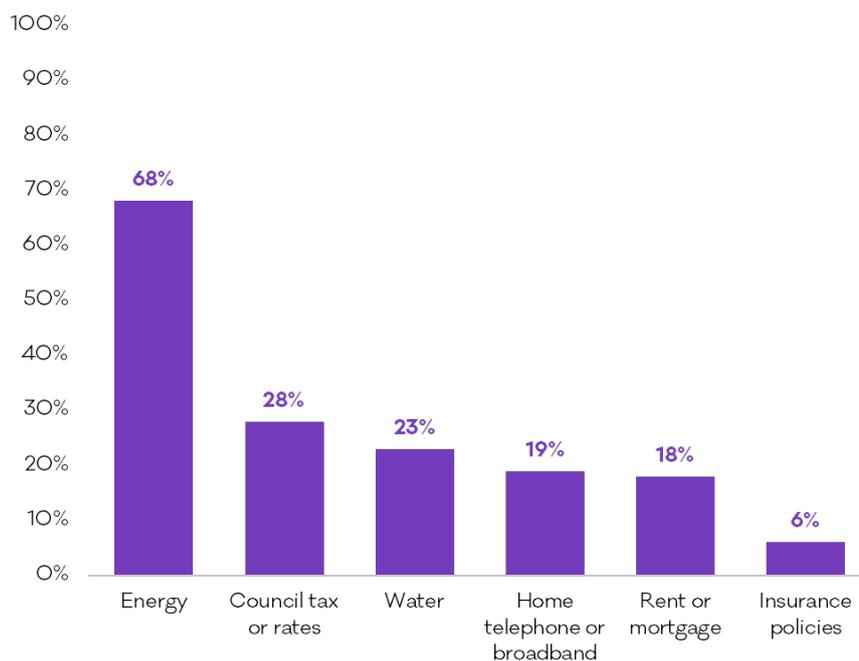
As a result of the financial challenges families raising disabled children face, many struggle to cover their everyday living costs and bills.

“I have had to cut short maternity leave because of our family’s financial situation. We are not using any heating – we will not be able to afford to heat our house. I’m borrowing money from family and friends – life is getting very difficult.”

Parent, North West England

Nine in 10 families raising disabled children (92%) currently say they are struggling or falling behind on their regular household bills.

Which regular household bills are you currently struggling with or falling behind on? (n=1,066)



Driven by rising costs and the need for families to use more resource due to their disabled children's conditions and illnesses, the most common bill families report falling behind on is their energy bill.

- Two thirds of families raising disabled children (68%) are now struggling to pay their energy bills.
- In the last year, families falling behind on their energy bills has increased by 23%.
- Two in five (42%) report they can't afford to keep their accommodation warm - an increase of 13% since December 2021.

"I am more worried about how life will be when the winter comes and energy costs increase further. I am already having to start to prepare and think how we can keep warm without using the heating by making blankets."

Parent, East Midlands



Cutting back

In order to manage financially, many families raising disabled children are being forced to cut back on both non-essentials and essentials.

“The rising cost of living is giving me more concerns than anything else. We already sacrifice everything for ourselves. Me and hubby don’t buy anything for ourselves or go anywhere. I already buy used clothes and sell on the children’s outgrown items to afford other things for them. There’s not much more to give.”

Parent, North West England

“The worse the financial issues are becoming, the worse it’s isolating whole families that have children with disabilities, it means we can’t enjoy leisurely activities.”

Parent, Scotland

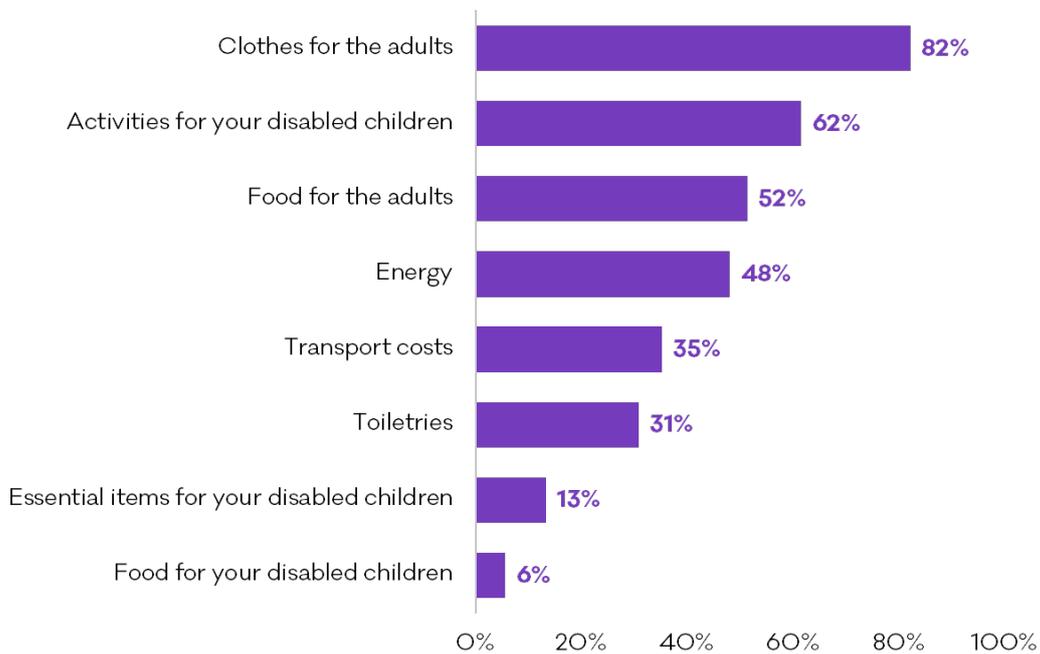
“For me personally, my gas and electric has shot up, in November it went from £150 a month to £212, then in April it went up to £278. I’ve stopped eating breakfast, and rarely eat lunch, as I try to make sure my kids have everything they need.”

Parent, West Midlands

- More than half of families (52%) report cutting back on food for adults in the household ;
- More than half of parents and carers (53%) have eaten less;
- More than half of parents and carers (54%) have cut the size of their meals or skipped meals completely
- There has been a 9% increase in families who have had to cut the size of meals or skip them entirely and an increase in the frequency of families doing this from 14% in September 2021 to 19% in June 2022
- Two in five families (41%) are deemed to be currently living in very low food security (USDA Household Food Security Survey Module);
- Almost half of families raising disabled children (48%) reported having to cut back on their energy use in the last year;
- The number of families cutting back on their energy use has increased by 9% in the last three months alone, rising from 39% in March 2022 to 48% in June 2022;
- Three in five families (62%) reported cutting back on play, leisure and recreational activities with their disabled children during the last year;

- 82% have cut back on buying clothes for adults in the household;
- Three in four (78%) of wider family members say they cannot afford to spend even a small amount of money on themselves each week.

**Which have you cut back on in the past 12 months because there wasn't enough money?
(n=1,066)**



Frequently families are being forced to cut back activities with their disabled children. Three in five families (62%) reported they have had to cut back on the play, leisure and recreational activities they do with their disabled children during the last year because there wasn't enough money.

"We had to stop our weekend swimming and football classes. The football classes are far away and the fuel prices mean that we can't afford to travel much by car."

Parent, Scotland

Going into debt

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

“The price of living is so high, yet wages so low, and it’s hard to make ends meet. We only get by because we have racked up £20k in loans and store cards and credit cards to get by, and help pay mortgage, water, council tax and fuel bills.”

Carer, South East England

In total, four in five families raising disabled children (83%) report being in some form of debt, with the average debt, excluding any mortgage or student debts, standing at more than £5,800.

Moreover, debt levels among families are rising. Two in five families raising disabled children (43%) have reported that their debts have increased by more than £500 in the last 12 months. The main increases have been in energy (25%) and credit card debts (24%)

“Energy debt is being taken out of ESA (Employment and Support Allowance) as it is the only way we can pay for the energy we’re using. So we have a lot less money for food and petrol. We cannot afford to go for days out and feel very isolated as we live in a remote area.”

Parent, Yorkshire and Humber, England

Almost two in five families raising disabled children (38%) believe they will need to go into further debt in the next six months.

The most common debts families raising disabled children are taking on include:

- Credit card debts (41%);
- Catalogue or mail order debts (28%);
- Debts with families and friends (27%);
- Personal loans (27%).

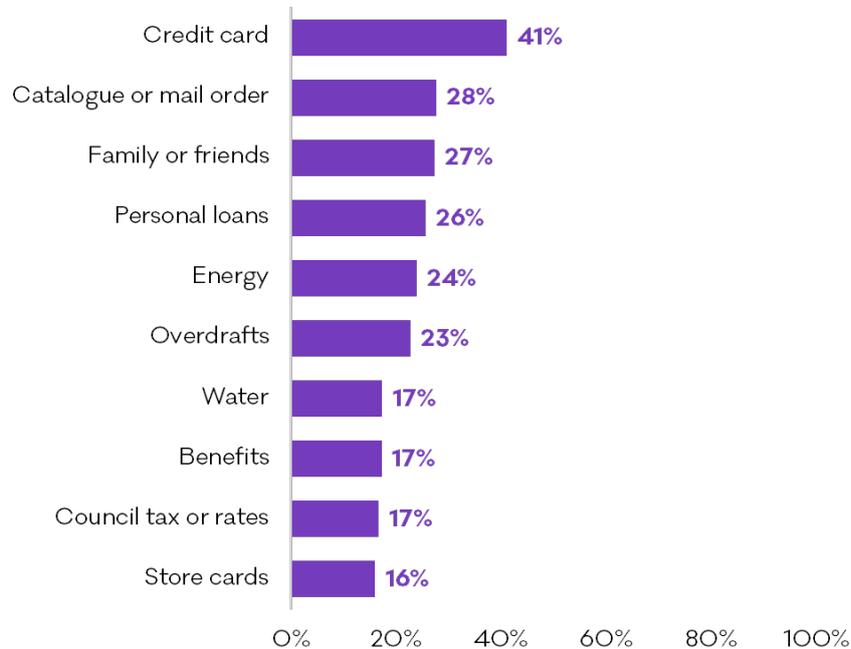
Only one in 10 families raising disabled children (9%) report having no difficulty keeping up with their debts.

While having debt is not necessarily a problem, three in 10 families raising disabled children (31%) are finding keeping up with the repayments a heavy burden.

Almost half of families raising disabled children (47%) have made just the minimum repayments on their debts for three or more months;

One in five (22%) have used credit to keep up with existing credit commitments.

Which debts do your household currently have? (n=1,066)



Going without

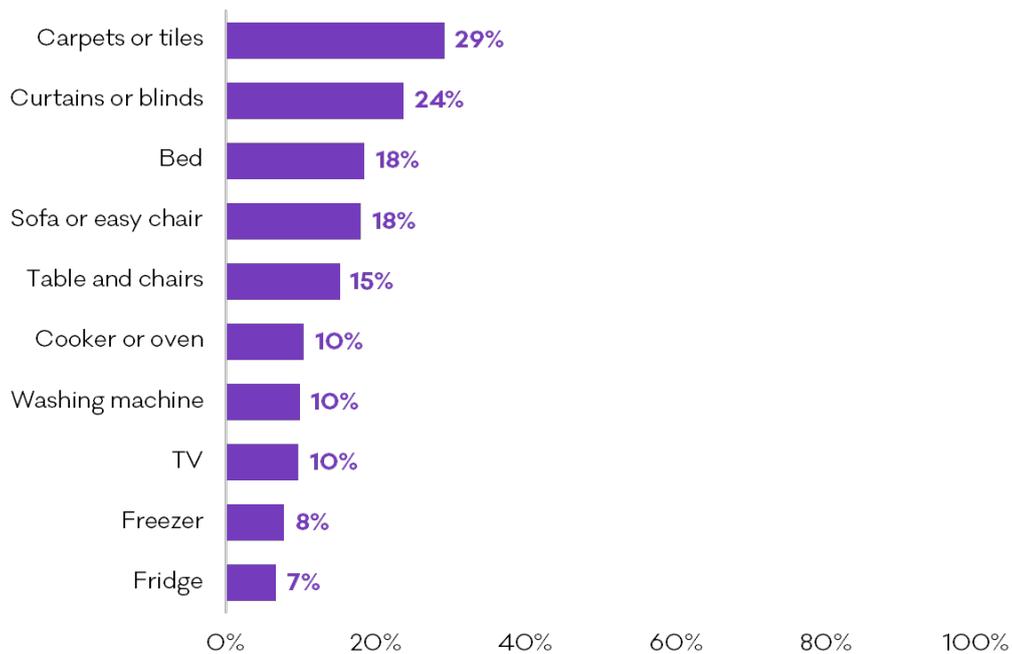
“We haven’t had a holiday or break since 2019, and I’ve had one 24 hour respite in 12 years. I have no family so no respite.”

Parent, East England

In many cases, these financial difficulties mean that families raising disabled children are forced to go without the things that others take for granted:

- Three quarters of families raising disabled children (76%) have been unable to afford to go on a family holiday or break for at least a week during the last year, missing out on valuable respite from their caring and opportunities for their children to play and build valuable memories;
- Four in five families (82%) cannot afford to replace worn-out furniture in their home;
- As a result, families go without a wide range of basic furnishings including flooring (29%), curtains and blinds (24%), beds (18%) and sofas (18%);
- Almost one in four families raising disabled children (23%) report not having at least one vital white good such as a fridge, freezer, washing machine or cooker during the last year;
- Four in five families raising disabled children (80%) report not having enough money to replace or repair major electrical goods when they break and so go without.

Which of the following has your household gone without, as a result of not being able to afford it, during the past 12 months? (n=1,066)



“We cannot afford to replace things when they break or manage the upkeep of our house.”

Parent, South East England

Many families have also been forced to go without essential appliances such as a fridge freezers, washing machines and cookers. Almost one in four families raising disabled children (23%) report not having at least one of these vital white goods during the last year.

“No washer, have to pay a lot more to get clothes clean. No cooker, have to pay more for cooked meals.”

Parent, Yorkshire and Humber

Impact on wellbeing



Disabled children



“My son’s mental health and not getting the support or help of local services. Not being able to afford to pay for private alternative therapies to support him and finding ways to help his emotional needs.”

Parent, London

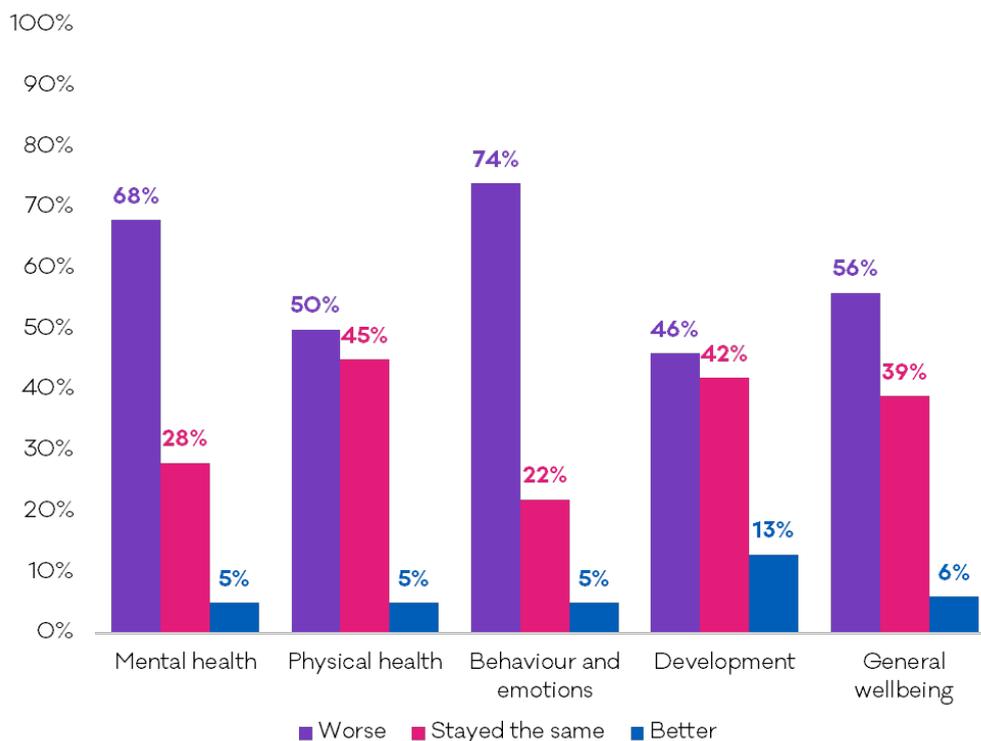
In the past year:

- Four in five families (83%) say their disabled children’s overall health and wellbeing has declined;
- Two thirds of families (68%) say their disabled children’s mental health has declined;
- Half of families (50%) say their disabled children’s physical health (50%) and general wellbeing (56%) have worsened;
- Nearly three quarters (74%) of families say their disabled children’s behaviour and emotional health have worsened;
- Nearly half (46%) say their child’s development has worsened.

“Dealing with my son’s behaviour at home alone is very difficult and has a big negative impact on everything, I wish there was more support for me at home, for people to see what it’s like and offer an understanding ear.”

Parent, East Midlands

How would you say the following have changed for your disabled children over the past 12 months? (n=1,066)



Non-disabled children

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

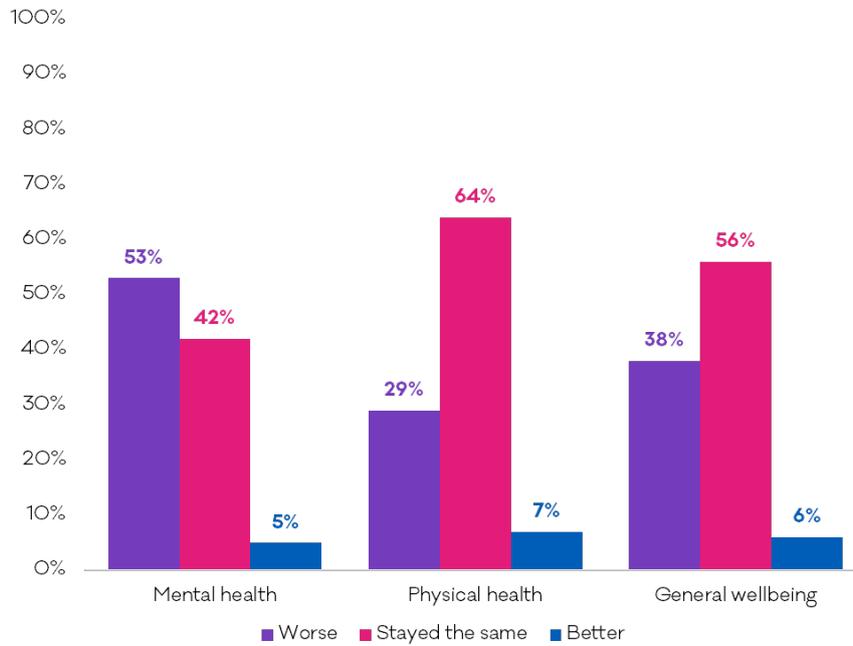
“Mental health of non-disabled child, feeling left out, having to grow up quicker than a normal child not living with such challenges.”

Carer, Scotland

In the past year:

- Three in five families (58%) say their non-disabled children’s health and wellbeing has declined;
- Half of families (53%) say their non-disabled children’s mental health has got worse;
- More than one third (38%) say the general wellbeing of their non-disabled children has declined;
- Almost one third (29%) say the physical health of their non-disabled children has worsened

How would you say the following have changed for your non-disabled children over the past 12 months? (n=657)



Parents and carers

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

Many parents and carers feel increasingly isolated and lonely, due in large part to the significant time they spend caring for their disabled children and the lack of sufficient respite or support.

“As a family without support from family/friends we often feel isolated and in need of respite care for our child to allow us to recover from our own exhaustion and fatigue built up from caring for a disabled child.”

Parent, North West England

Almost half of carers (49%) say that they often feel isolated from others;

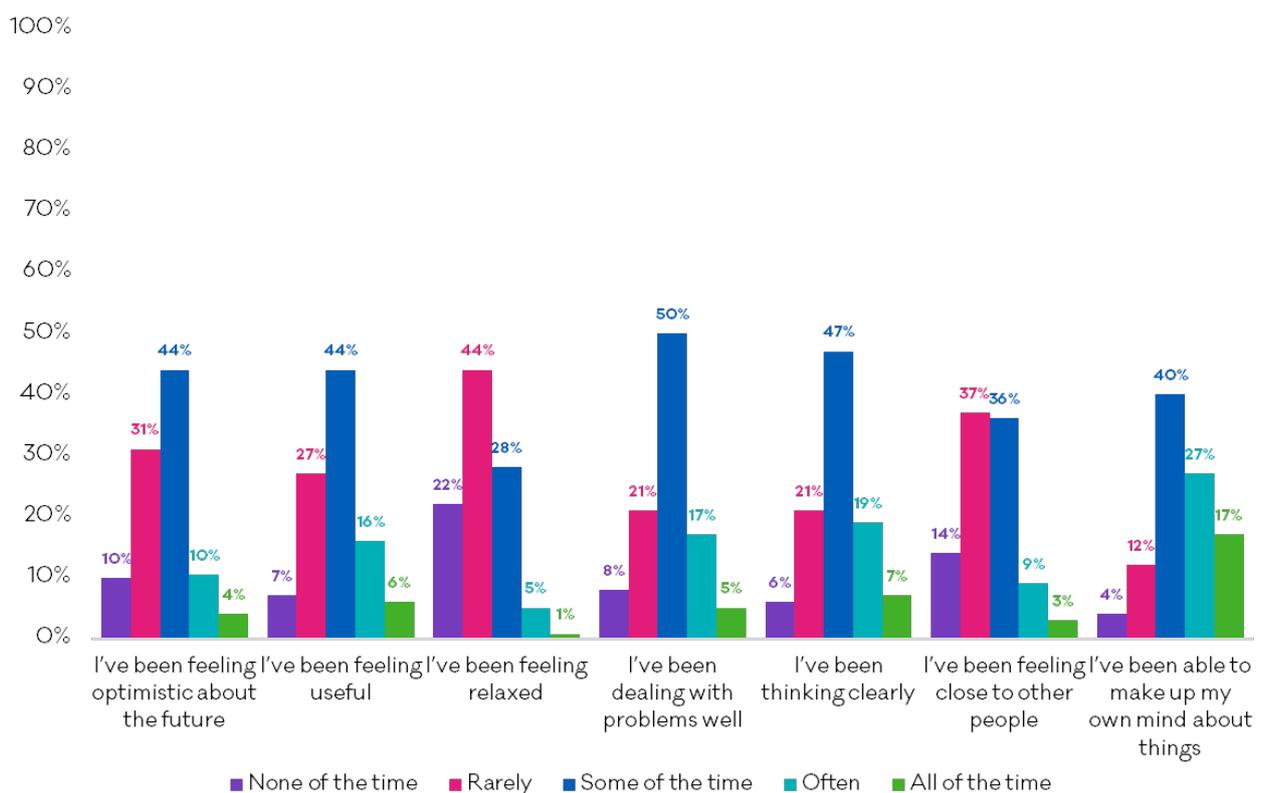
- Two in five parents and carers (42%) often feel lonely (based on their answers to a series of questions using an established scale - UCLA Loneliness Scale);
- Carers of disabled children are five times more likely to say they often or always feel lonely, when compared to the general population (7% of general UK population report feeling lonely 'often or always');
- Over three quarters of carers (77%) have a wellbeing score that indicates they experience some form of depression (based on the Shortened Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS));

The average wellbeing score of carers is significantly below that of the general UK population - 18.59 compared to 23.61. In particular, carers reported low levels of wellbeing in relation to feeling close to other people and feeling relaxed.

“My stress levels are constantly high and I am constantly in standby mode, running mental checklists of medications, injections and appointments. It can be so lonely and overwhelming at times, along with struggling with PTSD due to the months spent in intensive care with my son.”

Parent, South West England

For each statement, please choose the option that best describes your experience of each, over the past two weeks. (n=1,066)

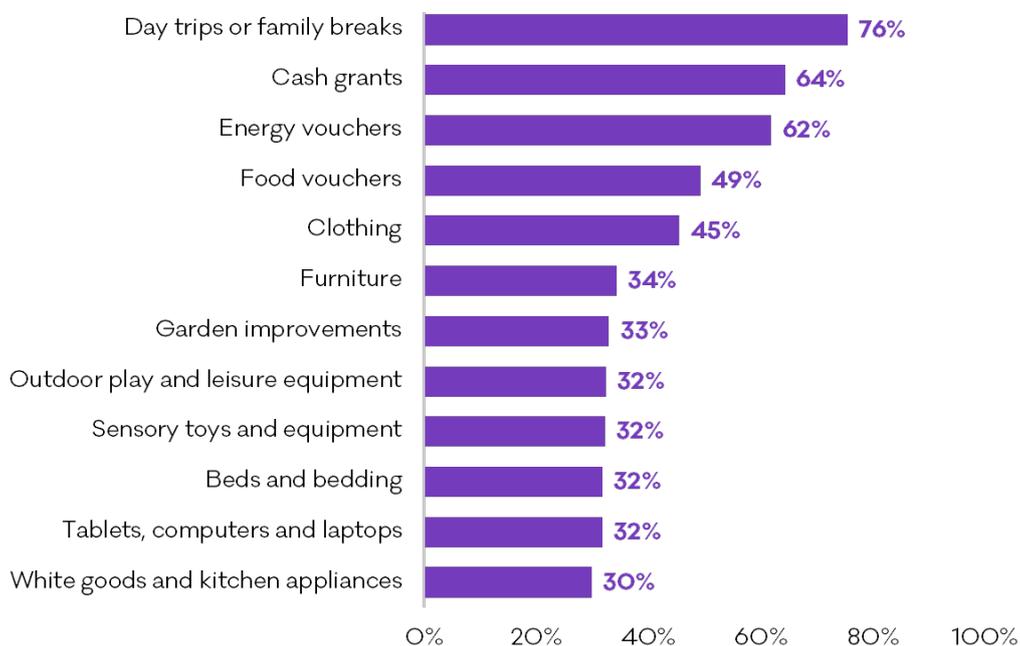


*Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2008, all rights reserved.

What families need most

Families have identified a range of actions to help address the worries and challenges they face raising disabled children.

Which grants could Family Fund potentially provide that would be most helpful to your family right now? (n=1,066)



The need for respite from daily caring responsibilities, is closely followed by a need for grants to help families cover essential costs and household bills. Families cited the following as their biggest priorities:

- Cash grants (64%)
- Energy vouchers (62%)
- Food vouchers (49%)
- Clothing grants (45%)

In addition, half of families (50%) identified the need for grant items to help their disabled children play and be active, including outdoor play and leisure equipment, sensory toys and equipment, and specialist trikes and bikes. Not only are these the grants most families said would be most helpful, they are also the areas that have shown the biggest increase in applications to Family Fund since September 2021, highlighting the growing challenge families are facing meeting everyday costs.

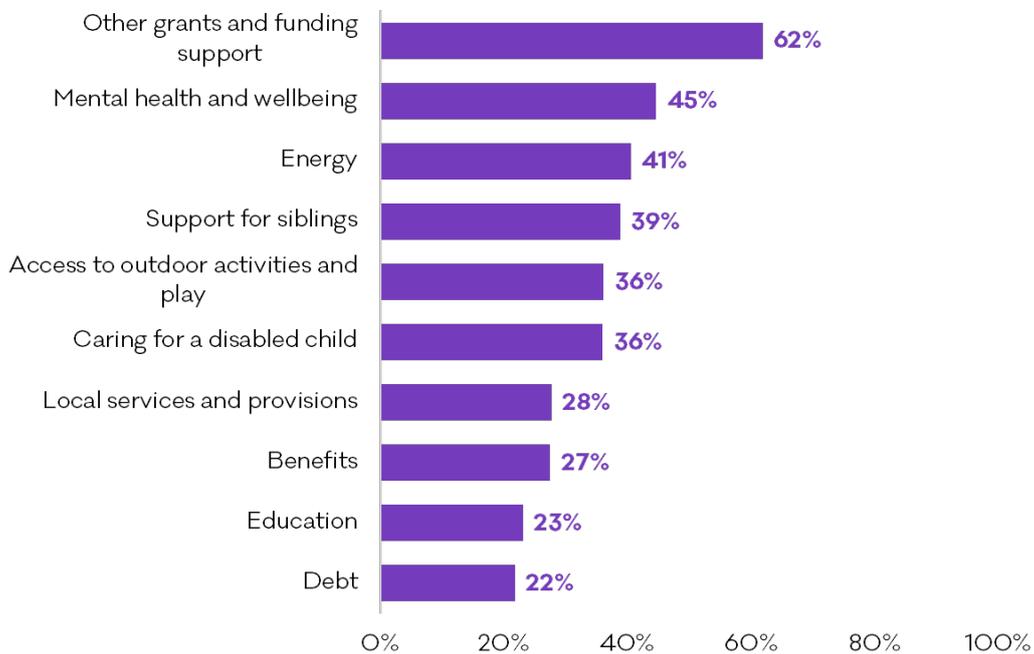
Information and support

Help to find other grants and funding was selected by three in five families (62%), as the overwhelming information and support priority.

Other information and support priorities included:

- Mental health and wellbeing (45%)
- Accessing energy support (41%)
- Caring for their disabled child (36%)
- Caring for their non-disabled children (39%)
- Accessing play and leisure activities (36%) for their children

Which topics could Family Fund potentially provide information and support on that would be most helpful to your family right now? (n=1,066)



Conclusion

Our research shows that families who care for disabled, or seriously ill, children face increasingly grave challenges.

The time, effort and energy families spend caring for their disabled children, mean that without significant increases in respite and support, the ability of parents and carers to increase their incomes or improve their financial situation, through work and wages, is significantly limited. At a time when the cost of living is rising rapidly, this continuing lack of opportunity to increase income is placing families in financial jeopardy.

Despite the best efforts of parents and carers to provide, and create, the best possible environment and opportunities for their disabled children to thrive, this lack of support and the financial situation they are faced with, mean they are forced to make a range of sacrifices to provide even the very basics, such as food, warmth and a safe and stable place to live.

Many families are cutting back, and going without both eating and heating, along with a range of other opportunities and essential household items. The sacrifices being made are, in turn, having negative impacts on the wellbeing of many families raising disabled children, with low and declining general and mental health.

Although there have been some signs of services coming back after the pandemic, the evidence and experiences of families show that levels of support continue to be insufficient to make any real difference.

The lack of respite, care and support puts a greater emphasis on other financial solutions, such as the social security system and charities like Family Fund, to address the shortfall in income.

Unfortunately, our research indicates that this financial support, while very welcome, is nowhere near enough to meet the extra costs of raising disabled children. It is not enough to prevent many families facing poverty. Many families worry about what the future holds and what they will be able to do to support their disabled children this winter, and beyond.

It is therefore critical that we work urgently with our government partners, and others to help relieve families' acute financial hardship.

Such hardship undoubtedly risks the right of children to a standard of living which supports their physical, mental, spiritual, moral and social development. Partners and Government must therefore play their part in ensuring the resource to support this right where families are unable to.

There needs to be a focus on ensuring more families can access respite, care and support, so parents and carers have the chance to improve their quality of life, personal development and ability to bring in additional income. Partners along with Government must address the underlying issues that leave families raising disabled children worse off.



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