



**The end of lockdown? The last six months in the
lives of families raising disabled children
UK Findings - September 2020**



Family Fund
Helping disabled children



Contents

- 💖 Family Fund
- 💖 Research introduction
- 💖 Summary of findings
- 💖 Income
- 💖 Expenditure
- 💖 Savings
- 💖 Debts
- 💖 Education
- 💖 Formal support
- 💖 Informal support
- 💖 Health and wellbeing
- 💖 Shielding
- 💖 Concerns
- 💖 Needs
- 💖 Conclusions





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

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.

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.



Introduction

The aim of the research is:

- 🧡 To understand how the coronavirus outbreak is affecting families raising disabled or seriously ill children in the UK.
- 🧡 To understand the concerns and needs of families raising disabled or seriously ill children in UK resulting from the coronavirus outbreak.

The research was undertaken by Family Fund. To date, Family Fund have conducted three waves of online surveys, as well as in-depth interviews with a sample of families.

This document sets out the findings from across the three waves of surveys. The latest survey was undertaken in August 2020. The previous surveys were undertaken between late March / early April 2020 and late April / early May 2020.

In total more than 7,000 families raising 9,000 disabled or seriously ill children have participated in the research. The sample for the first survey consisted of 1,986 families raising 2,700 disabled or seriously ill children. The sample for the second survey consisted of 2,531 families raising 3,279 disabled or seriously ill children. The sample for the third survey consisted of 2,557 families raising 3,204 disabled or seriously ill children.



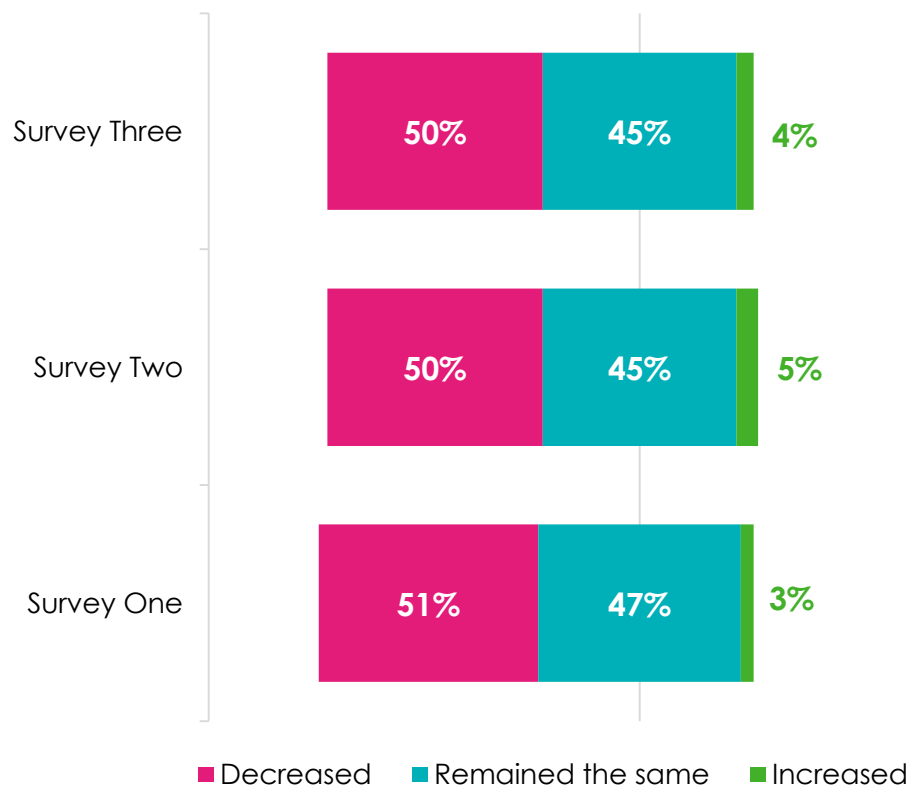
Summary of findings

- ♥ Half of families have lost income as a result of the coronavirus outbreak, and more than three quarters are experiencing increased household costs.
- ♥ Two in five families have seen their savings reduce, leaving seven in 10 families with no money to fall back on and increasing levels of debt.
- ♥ More than three in five families have seen the levels of formal and informal support decrease since the coronavirus outbreak, with many still going without vital forms of support.
- ♥ The mental health and wellbeing of the majority of disabled or seriously ill children, as well as their siblings and parent carers, has been negatively impacted, and showing little signs of recovery.
- ♥ Addressing these health and wellbeing needs, as well as their growing financial and support needs are the most pressing priorities put forward by families.



Income

How has your total household income changed as a result of the coronavirus outbreak?



Half of families [50%] have seen their income fall as a result of the coronavirus outbreak.

The findings shows no significant change from the first wave of research that was undertaken in March/April 2020.

This would suggest the income loss occurred almost immediately after lockdown was imposed, and despite the positive financial measures put in place, many families have now experienced a significant period on reduced incomes and are not yet seeing returns to previous income levels.

For a third [33%] of those losing income, it was a result of a member of the family member being furloughed. Other reasons for a losing income included those in self employment or temporary work getting no [17%] or less hours [14%].

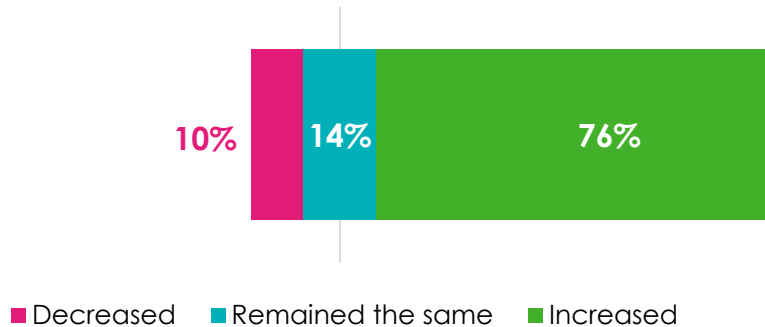
These rapid declines in income come on top of longer-term reductions in incomes for these families.

Findings from our previous research showed that two in five families [41%] experienced a reduction in their household income in 2019.



Expenditure

How have your household costs changed since the coronavirus outbreak?



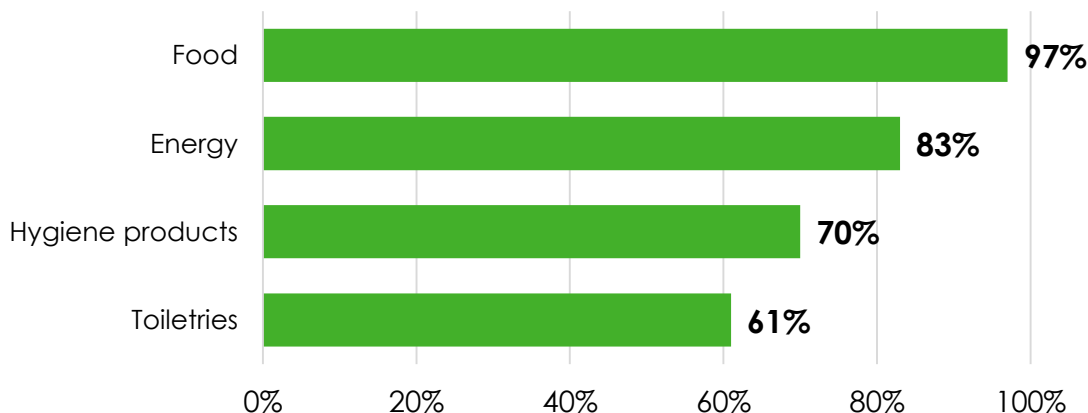
This situation of falling incomes is compounded for many families by increasing household costs.

More than three quarters of families [76%] reported that their household bills and costs had increased since the coronavirus outbreak.

These levels are consistent with the previous wave of this research undertaken in April/May 2020, indicating increased household costs still show little signs of relenting.

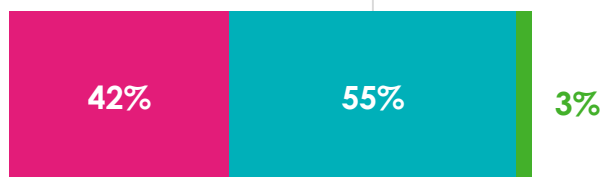
The increased time families are spending at home with their disabled or seriously ill children is in particular resulting in rising food [97%] and energy [83%] costs.

Which household costs have increased since the coronavirus outbreak?



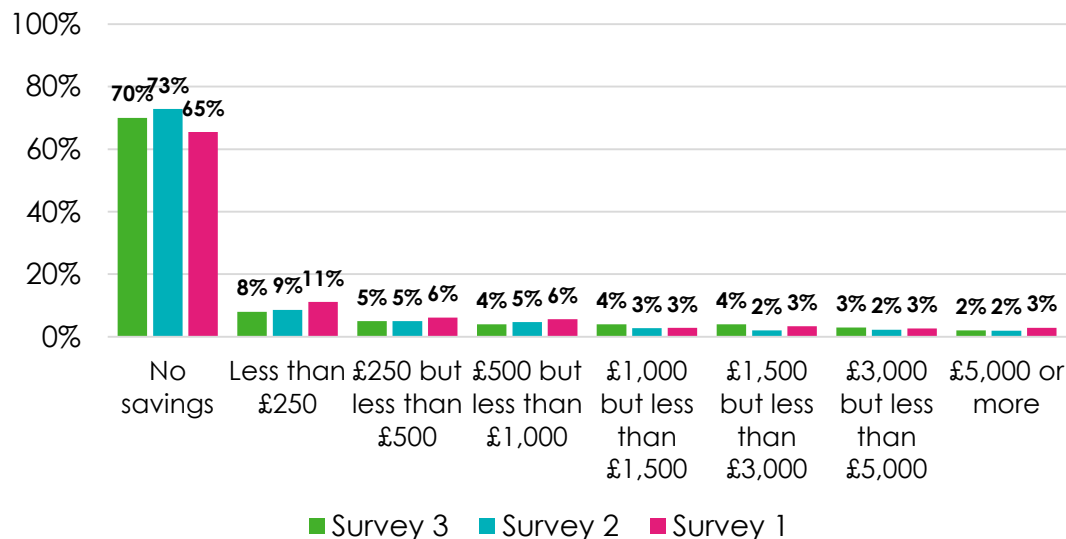
Savings

How have your household savings and investments changed as a result of the coronavirus outbreak?



■ Decreased ■ Remained the same ■ Increased

How much does your household currently have in savings and investments?



As incomes fall and household costs increase, many families are having to draw upon their savings.

This is evidenced by more than two in five families [42%] having seen their savings reduce as a direct result of the coronavirus outbreak.

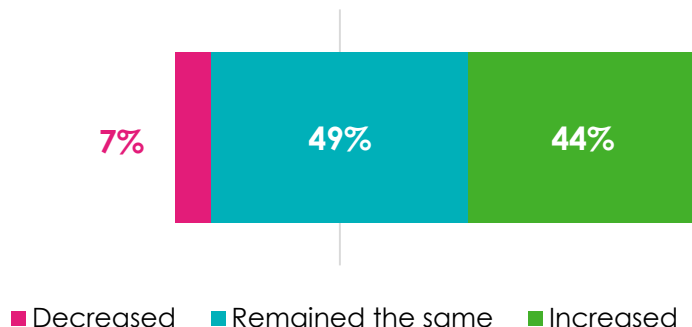
The lack of a financial safety net many families have to fall back upon is also evidenced by more than three quarters of families [78%] reporting having less than £250 in savings and investments.

While a slight improvement to the situation reported at the point survey two was undertaken, the findings reaffirm many families raising disabled or seriously ill children are unprepared for any further sudden expenses, emergencies or continuing rising costs.



Debts

How have your household and personal debts changed since the coronavirus outbreak?

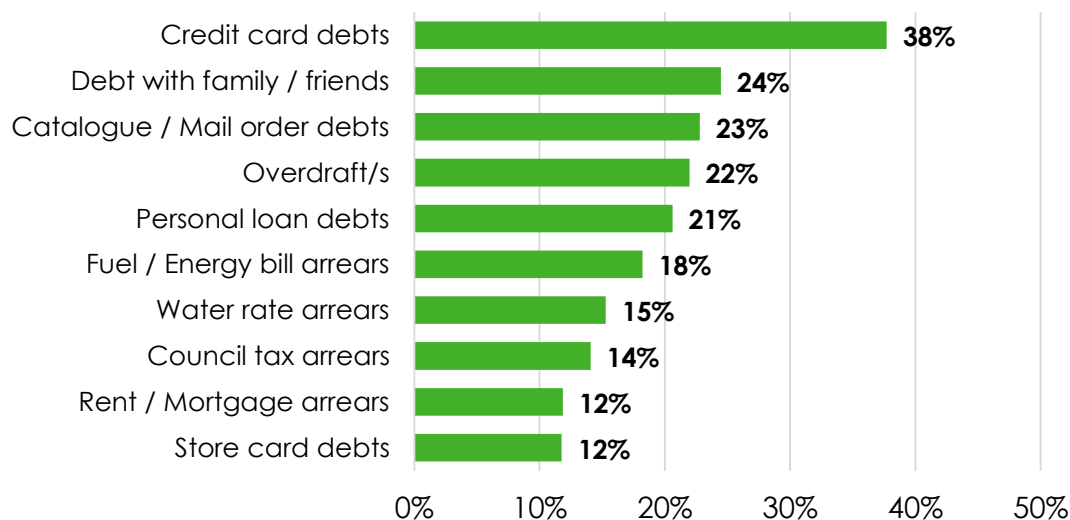


The financial difficulties resulting from the coronavirus outbreak are further evidenced by the increasing debts facing families.

More than two in five families [44%] reported their debts had increased since the coronavirus outbreak.

The most common debts held by families include credit card debts [38%], debts with family and friends [24%], catalogue and mail order debts [23%] and overdrafts [22%].

Which, if any, debts do your household currently have?



The challenges families are facing managing these debts is demonstrated by one in five [21%] reporting them as being a heavy burden.

With the fall in incomes, rising household costs, and limited and rapidly depleting savings to fall back on, growing levels of debt seem likely to become an increasing problem for many families.



"We had a large amount of savings, but since my husband lost his jobs these have been topping up Universal Credit to cover our bill's it's a worry when they run out how we will stay afloat. One issue is my daughter is wetting herself daily due to the anxiety of the virus, and due to so much change. This is meaning I'm washing a lot more, using kitchen roll, clothes are getting ruined etc. My other daughter is struggling so much she's not sleeping, I now feel ill due so much lack of sleep, I'm having to take unpaid time off work due to being so tired which is taking a strain, and my husband lost his job end of March."

"It's a struggle especially with pandemic and a single mother struggling to keep food medicines and toiletries stocked up. Paying increased bills as being home means usage of more internet, phone and utility water electrics and gas. On top food is something needed a lot. Kids eat out of boredom. I had to ask family to lend money for the food etc. and still struggling to pay off. Whenever wages and benefits come in they go out on my overdraft and card bills etc. right away leaving me with zero balance."

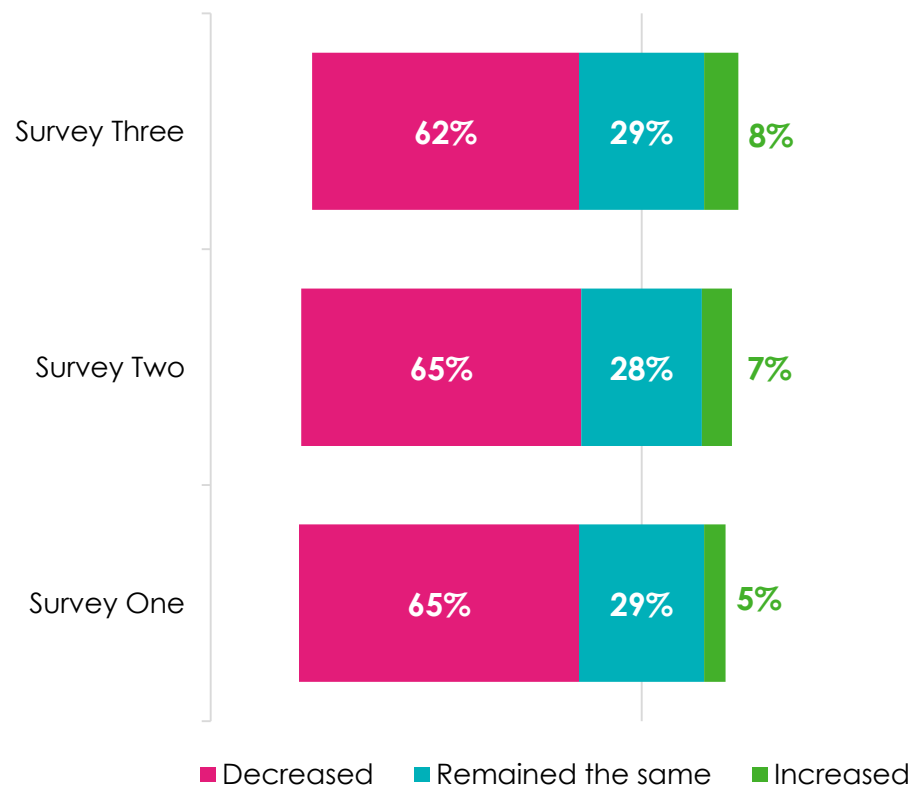
"Now life is slowly returning to normal from Covid-19, I'm worried about catching up with the debt it has left us in."

"That my self-employment earnings will not increase back up to their pre Covid-19 levels. Dreading the energy bills, especially the electricity from fans and other electrical items on all day long to regulate and soothe my autistic child."



Formal support

How has the formal support for your disabled or seriously ill children changed due to the coronavirus outbreak?



The financial circumstances alone are significant and potentially lasting, however, the research shows these are coupled with vital support being withdrawn, and families having to take on increased caring responsibilities for their disabled or seriously ill children.

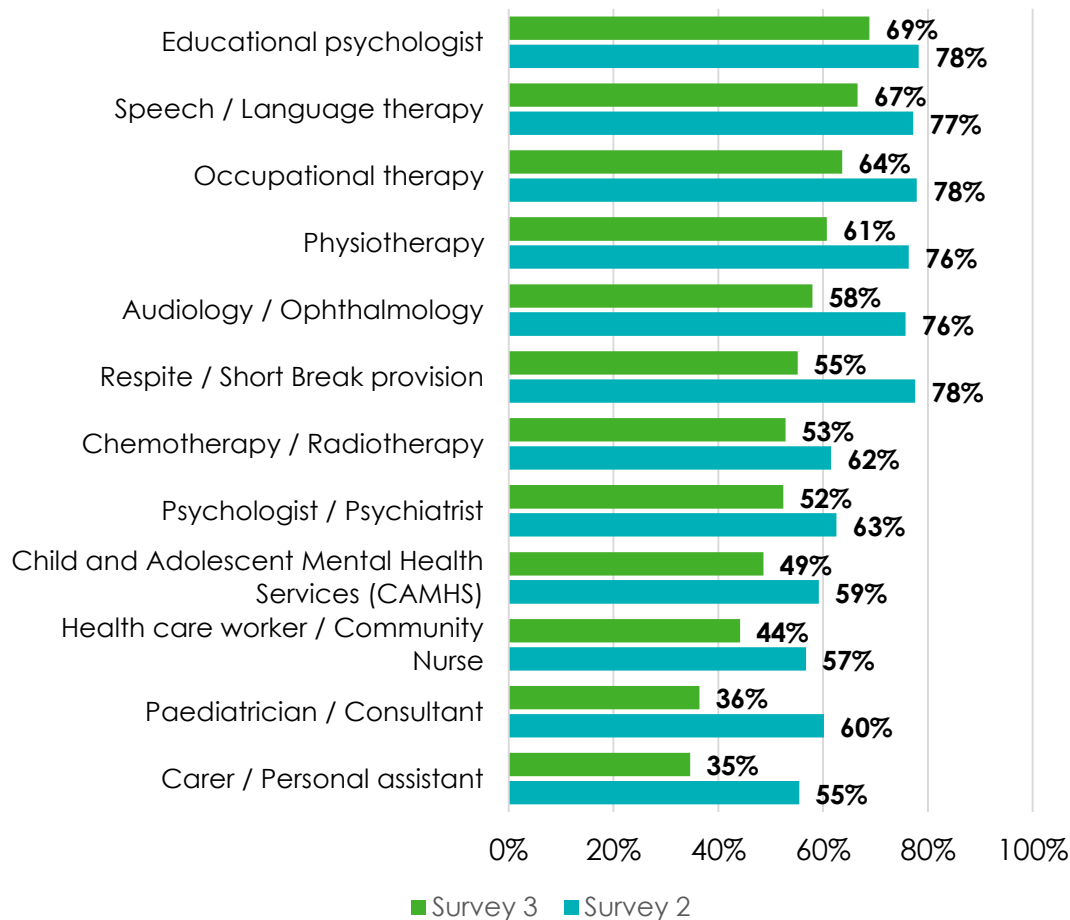
More than three in five families [62%] report formal support for their disabled or seriously ill children had declined since the coronavirus outbreak.

The results from the latest survey are consistent with the previous two surveys conducted, suggesting that in many cases it is still proving difficult to get formal support back in place for families raising disabled or seriously ill children.



Formal support

Which types of formal support are you and your disabled or seriously ill children no longer receiving following the coronavirus outbreak?



Since the last survey was undertaken in April/May 2020, there has been reduction in the formal support families and their disabled or seriously ill children have been forced to go without.

However, when examining the formal support they were receiving prior to the coronavirus outbreak, many families are still being left waiting for even basic levels of provision to return.

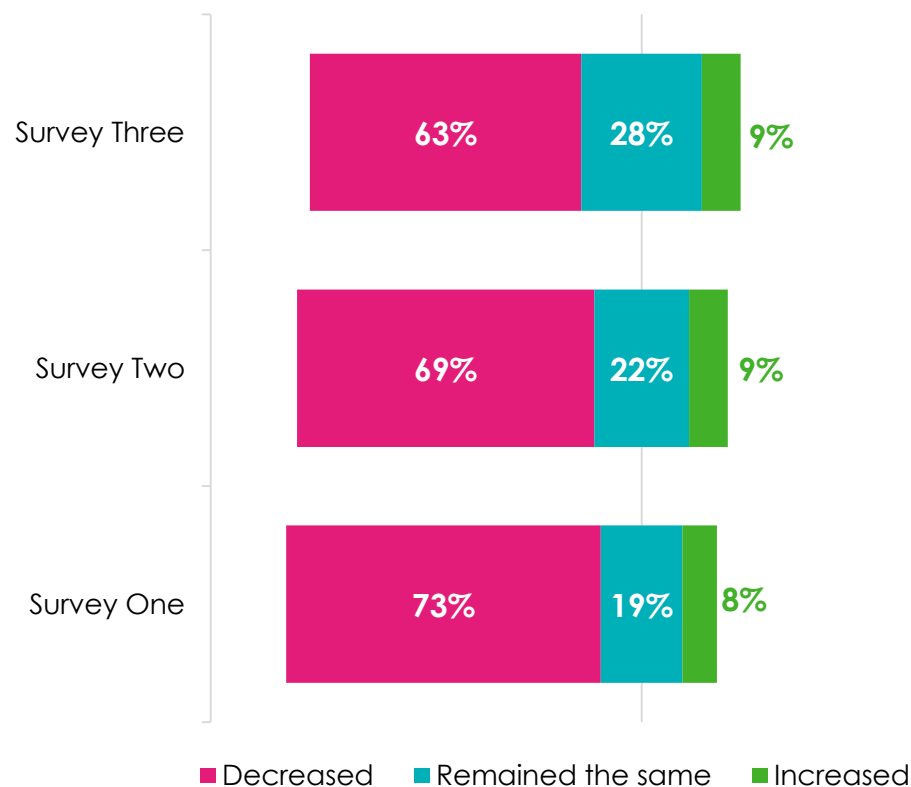
The most common types of formal support families are still going without include educational psychologists [69%], speech and language therapy [67%], occupational therapy [64%], and physiotherapy [61%].

With schools being closed and the range of other service providers being unable to find safe ways of delivering support, many families raising disabled or seriously ill children are still left going without.



Informal support

How has the informal support for your disabled or seriously ill children changed due to the coronavirus outbreak?



It is not only formal support that families have seen withdrawn.

More than three in five families [63%] have reported the informal support available to them has declined as a result of the coronavirus outbreak.

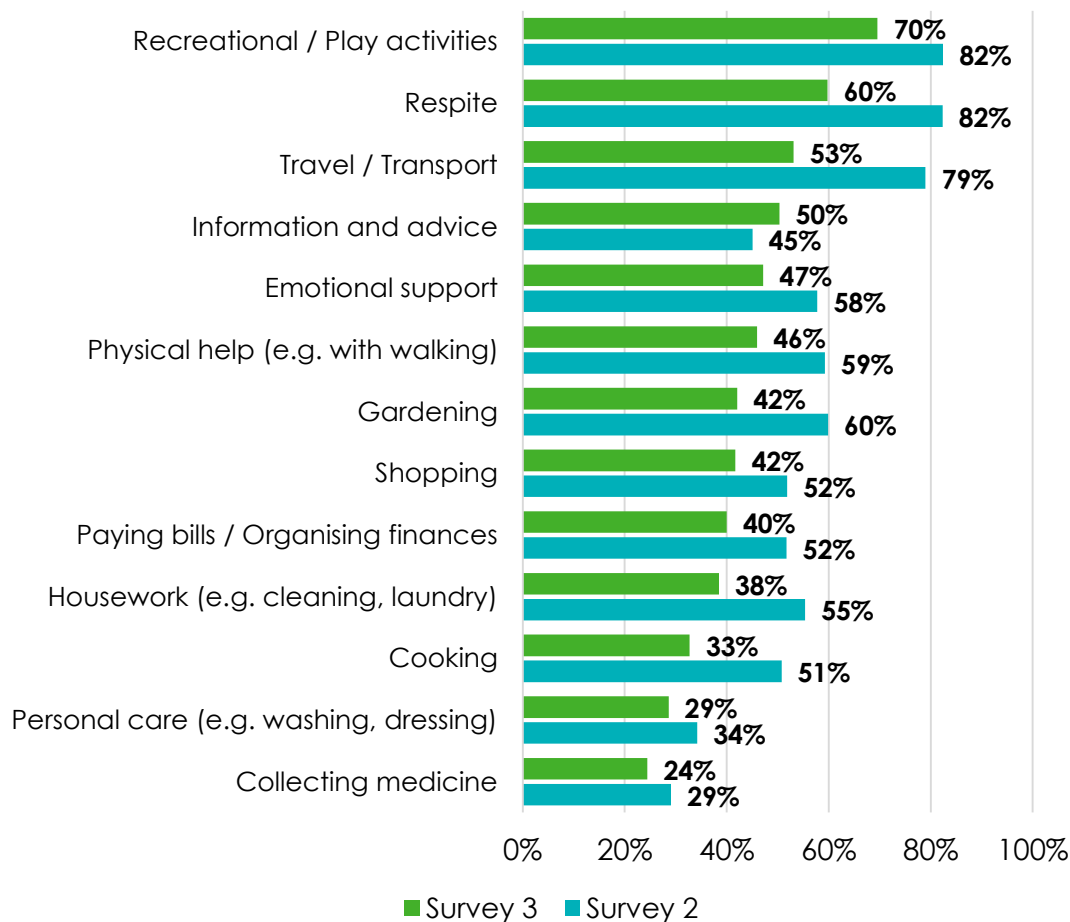
The current position is an improvement on the situation immediately after going into lockdown, when nearly three quarters of families [73%] reported the informal support they and their disabled or seriously ill had declined.

However, the results from the latest survey highlight the ongoing challenges facing families in accessing informal support.



Informal support

Which types of informal support are you and your disabled or seriously ill children no longer receiving following the coronavirus outbreak?



As with formal support, the number of families missing out on informal support has reduced since the early weeks of lockdown.

However, the latest survey reveals a significant number of families are still going without many types of informal support on which they depended prior to the coronavirus outbreak.

The main types of informal support families remain without include recreational and play activities for their disabled or seriously ill children [70%], respite [60%], transport [53%], and information and advice [50%].

This evidence, and that relating to formal support, indicate that there is still some way to go in returning to pre-pandemic levels of support for families raising disabled or seriously ill children.



"Our financial situation worries me and I worry it's affecting my son's progress due to have enough money to meet his needs. Me and my partner both worked for 11 years before having to give up work for our son. He rarely sleeps and this is having a massive effect on us returning to work, as well as his behaviour. We have just enough to cover our bills and still struggle but when it comes to repairing our house, we have no money for this because we have a mortgage. We've looked into going into housing but this seems a slow process. In the meantime I'm having to live in a house that's not suitable for my youngest and his development."

"My son's therapy needs have increased recently and I will need to take more time off work. I am also shielding as extremely vulnerable to coronavirus and worked from home since early March. I worry my employer will not look favourably on my working from home as we support a reception and internal staff and pupils."

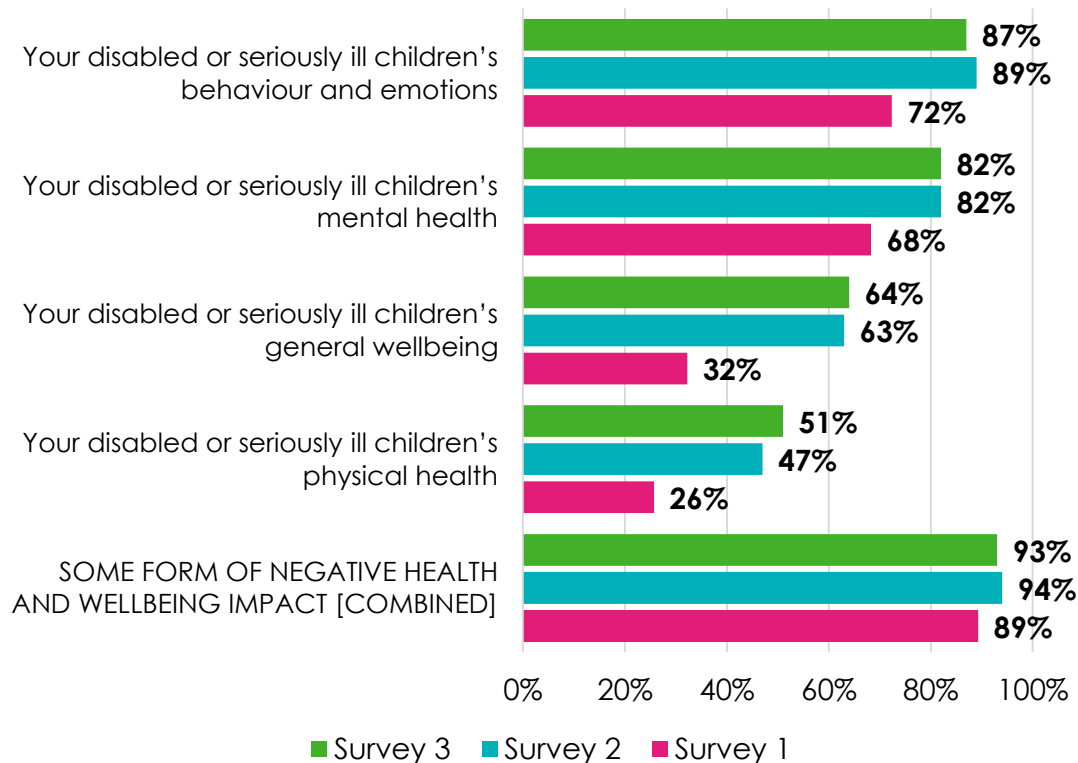
My absence from the office puts significant strain on other members of the team. I feel I will be pushed to return to work earlier than I feel comfortable with and that Managers may not support time needed to meet son's appointments and additional therapy. I have thought about requesting a reduction in responsibilities and therefore income so that I can support him more easily."

"We do not have enough income to live on. After bills, debt payments and groceries we have £20 a week to live on. Unsurprisingly, we fall further into debt every month - we cover the shortfall with credit cards. Neither me nor my husband work as we spend all our time caring for our severely disabled son who needs 24 hour care. We have both tried working part time but our severely disrupted and deprived sleep patterns due to our sons care needs make it unsustainable in the long term. It is hard to see a way out of our situation."



Health and wellbeing

Has the coronavirus outbreak impacted negatively on any of the following?



The research suggests that all of these factors are having a significant and sustained negative impact on the wellbeing of disabled or seriously ill children.

93% of families said the coronavirus outbreak had negatively affected their disabled or seriously ill children's health and wellbeing, an increase from 89% in first few weeks of the lockdown.

In particular, families are reporting this had negatively affected their disabled or seriously ill children's behaviour and emotions [87%], and their mental health [82%].

This includes their disabled or seriously ill children feeling increasingly anxious and stressed, becoming upset and experiencing more regular mood swings, and escalating challenging behaviour.

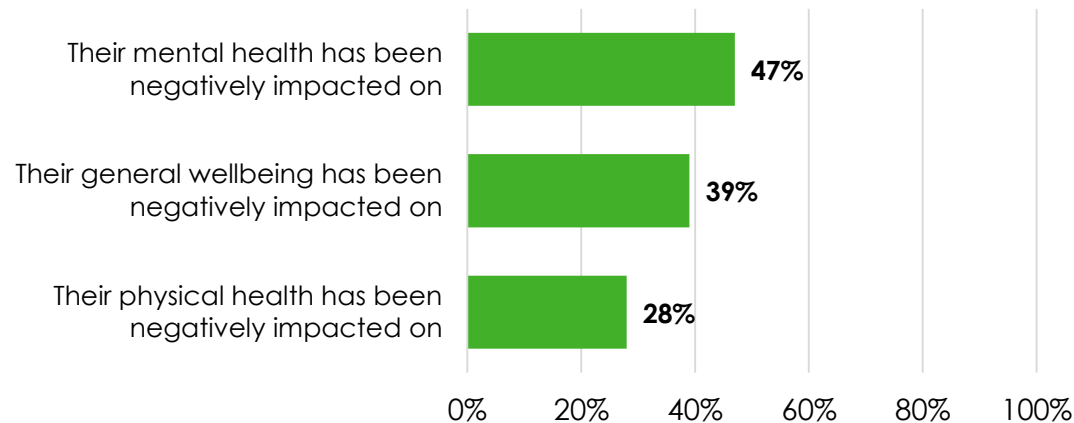
The evidence also suggests the coronavirus outbreak has set back the development and learning of many disabled or seriously ill children.

More than three in five families [64%] reported the coronavirus outbreak has had a negative impact on their disabled or seriously ill children's development, and nearly nine in 10 families [87%] said it had negatively impacted their learning.



Health and wellbeing

What, if any, challenges has having disabled or seriously ill children presented for their siblings since the coronavirus outbreak?



These impacts extend to the whole family, with no one seeming to escape this lasting negative health and wellbeing effects of the coronavirus outbreak.

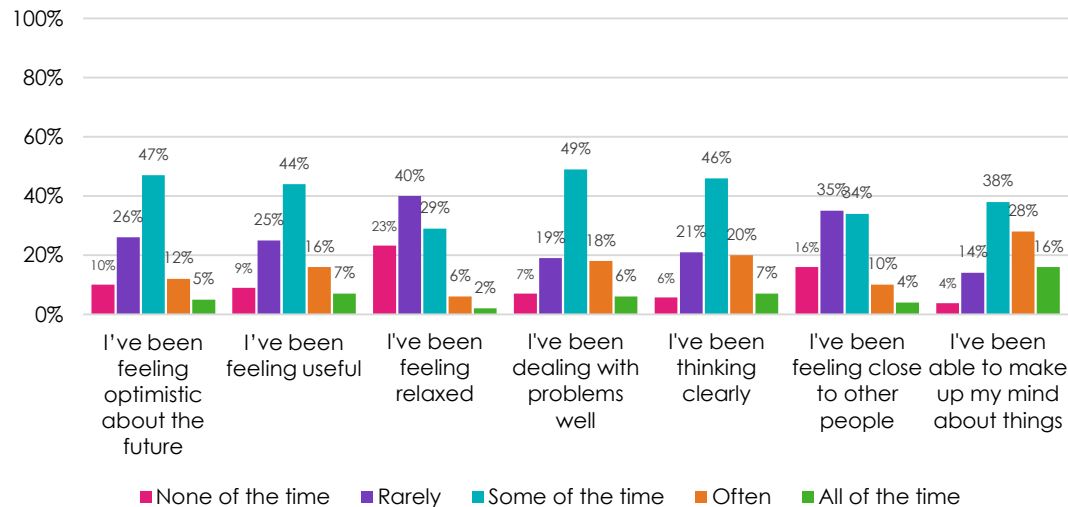
This includes the siblings of disabled or seriously ill children, with almost half of families [47%] saying they have had their mental health negatively impacted on since the coronavirus outbreak.

Two in five families [39%] also reported that siblings general wellbeing had been negatively impacted on, and more than a quarter of families [28%] said it had negatively impacted their physical health.

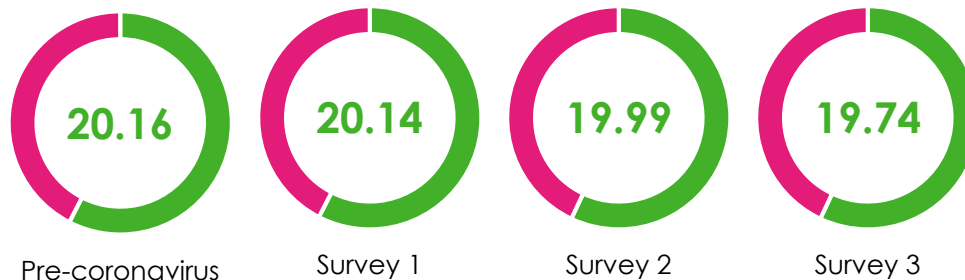


Health and wellbeing

For each of the following questions, please say how often you feel that way in the last two weeks?



Wellbeing score



As well as the impact on their children, the research also indicates an increasing negative effect on the health and wellbeing of parent carers.

The shortened Warwick Edinburgh Mental Wellbeing Scale was used as part of the research to help assess the mental wellbeing of parent carers, which provides a score ranging from seven [low level of wellbeing] to 35 [high level of wellbeing].

The latest survey revealed an average wellbeing score for parent carers of 19.74. While their mental wellbeing was already significantly lower than the general UK population, the results suggest the coronavirus has further set back the mental wellbeing of parent carers.

While this decline from pre-coronavirus levels is fairly minimal [2%], the continued negative trend in each survey suggests a lasting impact on parent carers' mental wellbeing.



"I was planning to get back to work this year. Now it seems impossible - there are no vacancies and my mental health as well as mental health of both children has worsened dramatically."

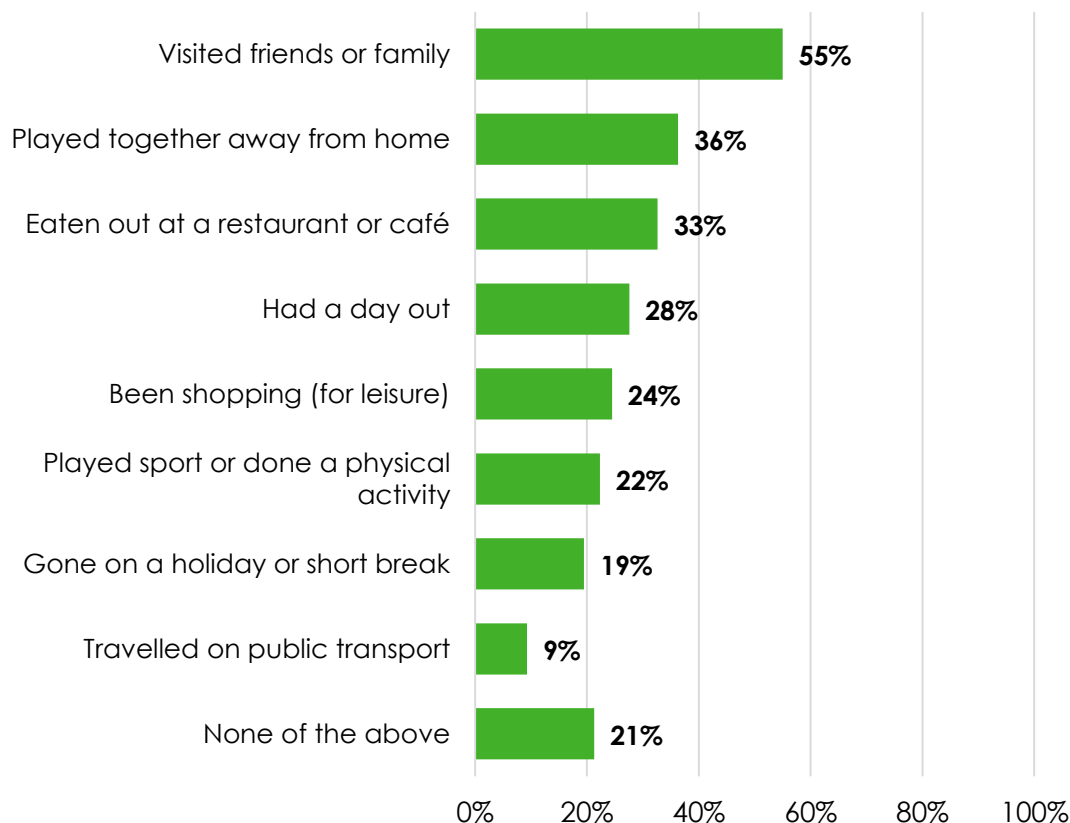
"Going for such a long time without any income at all due to self-employment, and not be allowed to trade during lockdown. Bills and rent went into debt and yet more money was needed for food and electric. Had to spend a great deal of money to sanitise everything to keep disabled daughter extra protected, as she waited for heart surgery during lockdown. Have been under huge financial and emotional stress for the past five months."

"We are so exhausted from caring, as a family unit we are breaking down from exhaustion. I fear when this is all over it's the children that suffer as we have no reserves left to purchase the equipment, assessment etc. needed. I've had to let my son down with dental treatment because we can't afford the £300 I need to find for his sedation as the NHS won't fund. I'm having to try find money for a disability buggy as request was rejected. I will be trying to juggle three school placements because transport isn't running at capacity. Just feeling we have let our children down but so tired from trying our best to find the food they will tolerate, endless sleepless nights from their anxiety and running on empty feeling isolated and lost in a big world forgotten how much it takes to support four children with disabilities."



Shielding

Which, if any, activities have your family done together since the Coronavirus lockdown restrictions have been relaxed?



As well as the potentially lasting financial and wellbeing effects of the coronavirus outbreak, even with the lifting of many restrictions, many families raising disabled or seriously ill children will be continuing to restrict their day-to-day activities.

A third of families [32%] said they will not be changing their actions in line with the easing of restrictions due to their children's conditions.

This apprehension is reflected in the activities families said they done since the lockdown restrictions have been relaxed.

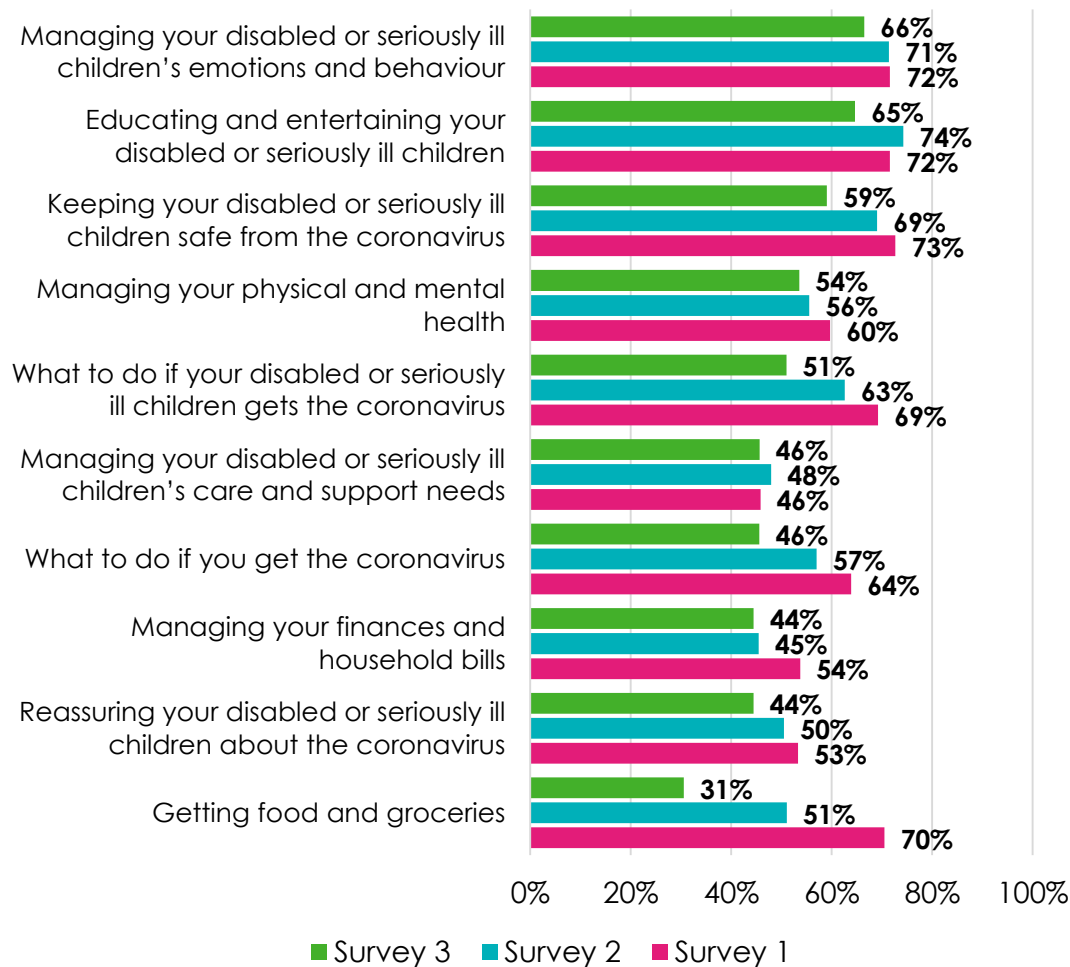
Only just more than half of families [55%] had begun visiting friends and family and less than three in 10 families [28%] have had a day out together.

This compares to three quarters of families [78%] who previously visited friends and family and half [47%] who took days out together.



Concerns

Which, if any, of the following things are currently worrying you most?



The biggest concerns for families right now focus around two core areas:

- 🧠 Educating and entertaining their disabled or seriously ill children at home.
- 🏥 Their disabled or seriously ill children's health and wellbeing.

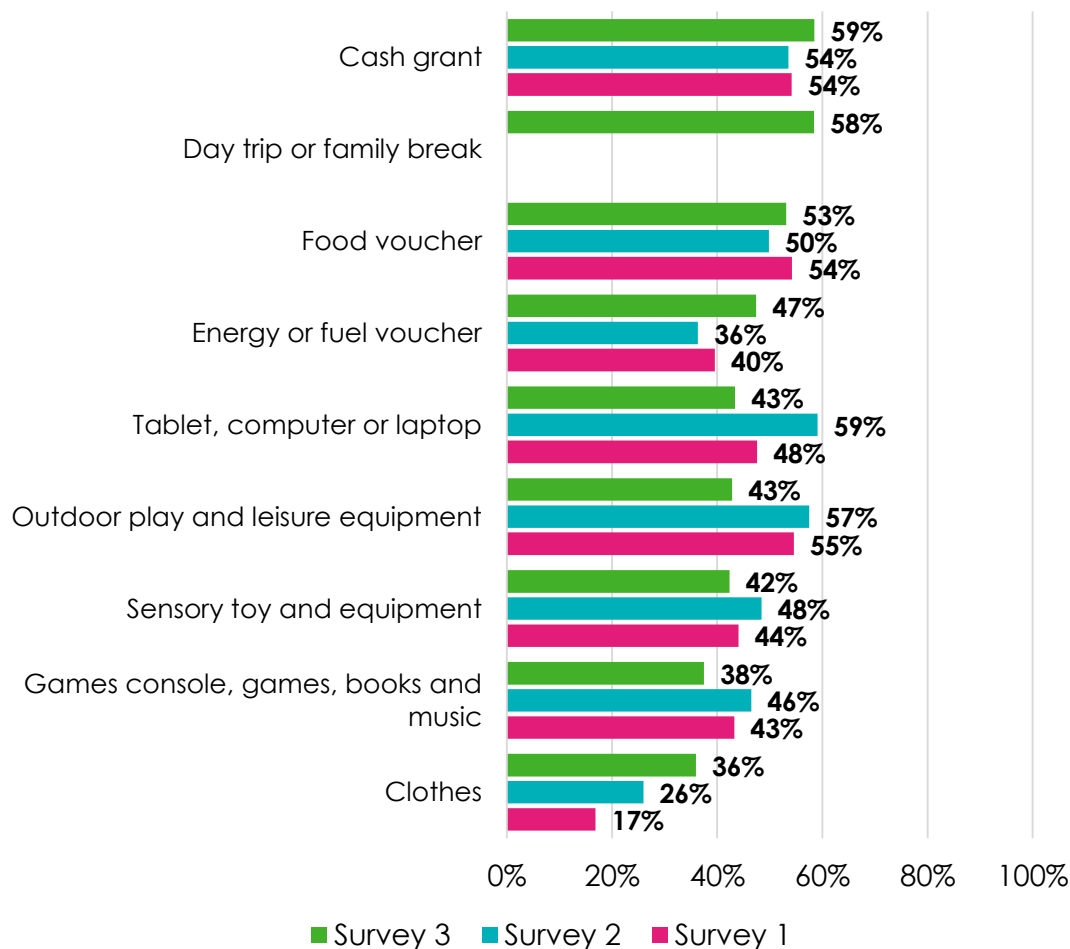
Managing their own health and wellbeing, as well as the household finances also remain high priorities for parent carers.

Concerns around food and essential items, as well as about coronavirus itself, while still high, have declined most significantly since the first few weeks of the outbreak.



Needs

Which, if any, of the following things could potentially be provided that would be most helpful right now?



The biggest concerns raised by families are reflected through to the things they felt would be more helpful right now.

Since the last survey in April/May 2020, the priority is turning to things that can help resolve the day-to-day and growing financial pressures families are facing. This includes cash grants [59%], food vouchers [53%] and energy and fuel vouchers [47%].

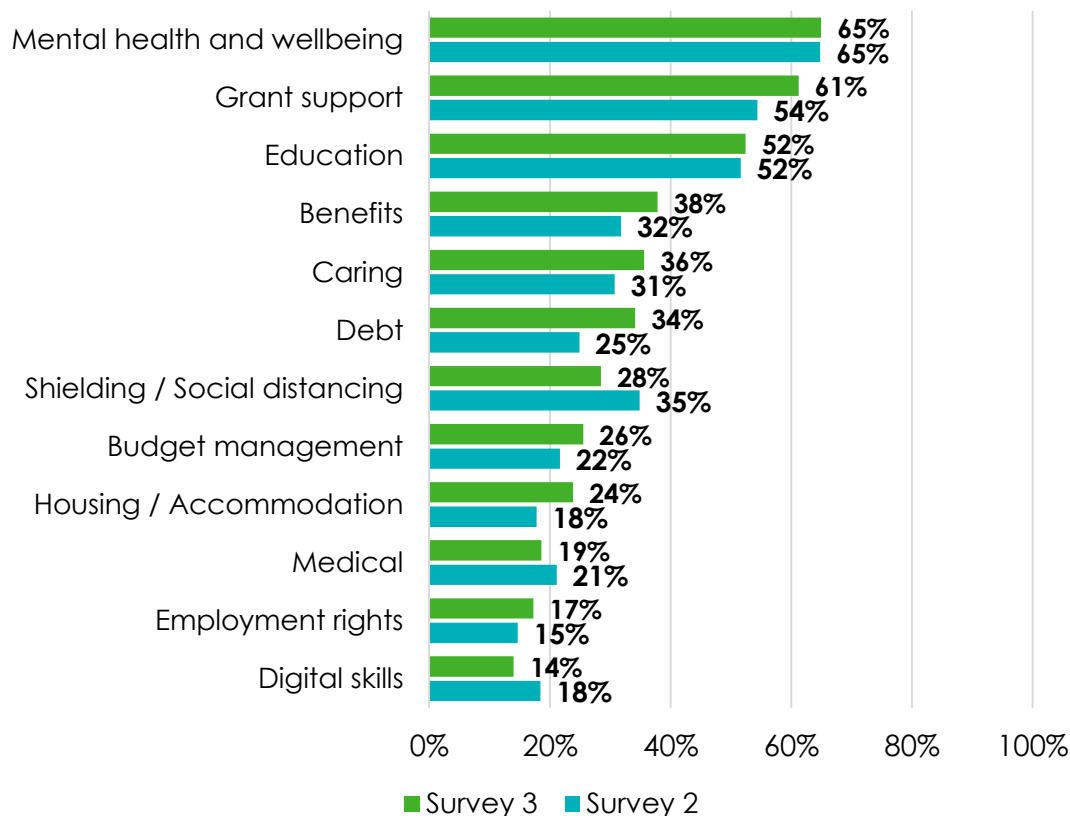
The need for respite and breaks is also reflected, with almost three in five families [58%] saying grants for day trips or breaks would be most helpful right now.

Whilst they have reduced to an extent since the last survey, items to help educate and entertain their disabled or seriously ill children, such as digital devices [43%], outdoor play and leisure equipment [43%], and sensory toys and equipment [42%], remain a high priority for families.



Needs

Which, if any, topics could we or other organisations potentially provide information on that would be most helpful to families right now?



The biggest concerns raised and issues arising for families are also reflected in their information and advice needs.

Mental health and wellbeing was raised by nearly two thirds of families [65%] as an information need.

In addition, the growing financial pressures facing families are also reflected through in their information and advice needs.

Since the last survey in April/May 2020, increasing numbers of families are now indicating they need grant, benefits, debt and budget management support.



Conclusions

As the research demonstrates, the increased pressures and ongoing lack of support appear to be having a lasting negative impact on the financial and mental wellbeing of families raising disabled or seriously ill children.

Even if they return to previous income levels in the near future, for many it looks likely to be a long recovery. Many families won't quickly be able to replenish their savings that for significant numbers have depleted to nothing, pay back the money they have borrowed and debts they have accumulated, or be able to catch up on their household bills they have fallen behind on.

Likewise, even if support returns to pre-coronavirus levels soon, the negative effect the outbreak has had on the mental and emotional wellbeing of many disabled or seriously ill children, as well as the setbacks it has had on their development and learning, will take some time to recover from. This also applies to the wider family, who without respite and support, have also seen their mental wellbeing continuing to deteriorate.

All of this seems to suggest the post-coronavirus world will likely bring a 'new normal' in which families raising disabled or seriously ill children are even further disadvantaged.





Sharing our findings

We have undertaken this work to understand how the coronavirus outbreak is affecting families raising disabled or seriously ill children across the UK.

Having gathered this evidence and listened to the voices of families, we are looking at how we can best act upon the issues raised. That is why we are keen to share our findings with key bodies, organisations and networks that can help address their immediate concerns and needs.

If you want to discuss the research, please contact:

research@familyfund.org.uk





Family Fund

Helping disabled children

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