



**Impact of the coronavirus on families raising  
disabled or seriously ill children**  
***Northern Ireland Findings – January 2021***



**Family Fund**  
Helping disabled children



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**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.



# Introduction

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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 four waves of online surveys, as well as in-depth interviews with a sample of families.

This document sets out the findings from across the four waves of surveys. The latest survey was undertaken in December 2020. The previous surveys were undertaken between March 2020, May 2020, and August 2020.

In total, 345 families raising 454 disabled or seriously ill children in Northern Ireland have participated in the research. The sample for the most recent survey consisted of 70 families raising 92 disabled or seriously ill children living in Northern Ireland.



# Summary of findings

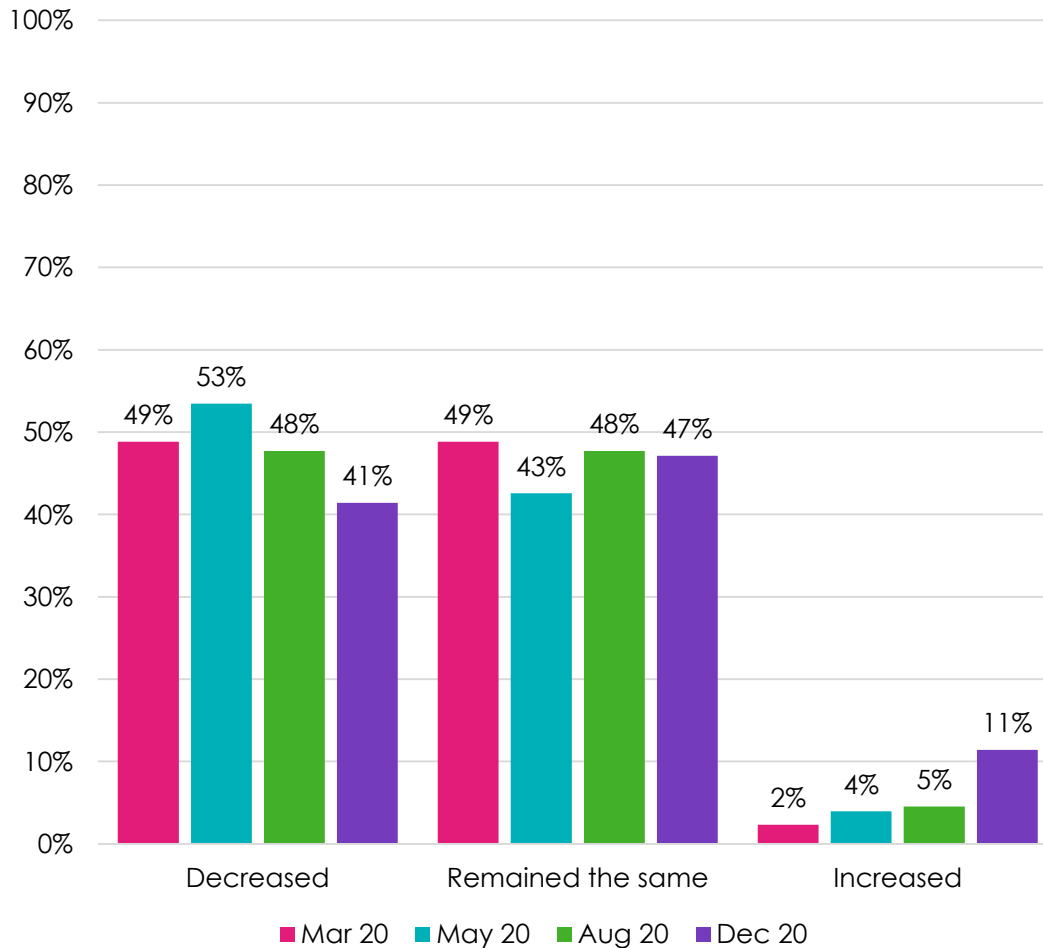
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- Two in five families [41%] are still reporting reduced levels of household income as a result of the coronavirus outbreak.
- Nine in 10 families [93%] are reporting that their household bills and costs are still at higher levels than they were before the coronavirus outbreak.
- Almost half of families [47%] have had to draw upon their savings to manage reducing incomes and increasing costs, leaving almost three quarters of families [73%] with no money to fall back on.
- Three in five families [61%] reported their debts have increased since the coronavirus outbreak.
- Almost seven in 10 families are still receiving reduced levels of formal [69%] informal support [67%] for their disabled or seriously ill children.
- More than one in 10 disabled or seriously ill children [13%] have not attended their educational setting since the new school year began.
- The mental health and wellbeing of nine in 10 disabled or seriously ill children [93%] has been negatively impacted upon by the coronavirus outbreak, and there are only limited signs of recovery.



# Income

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



More than two in five families [41%] have seen their income fall as a result of the coronavirus outbreak.

The findings show an improvement from the previous waves of the research, suggesting some families are now seeing their income levels return to pre-coronavirus levels.

However, the results would suggest the income loss that occurred almost immediately after the coronavirus outbreak, is still affecting many families.

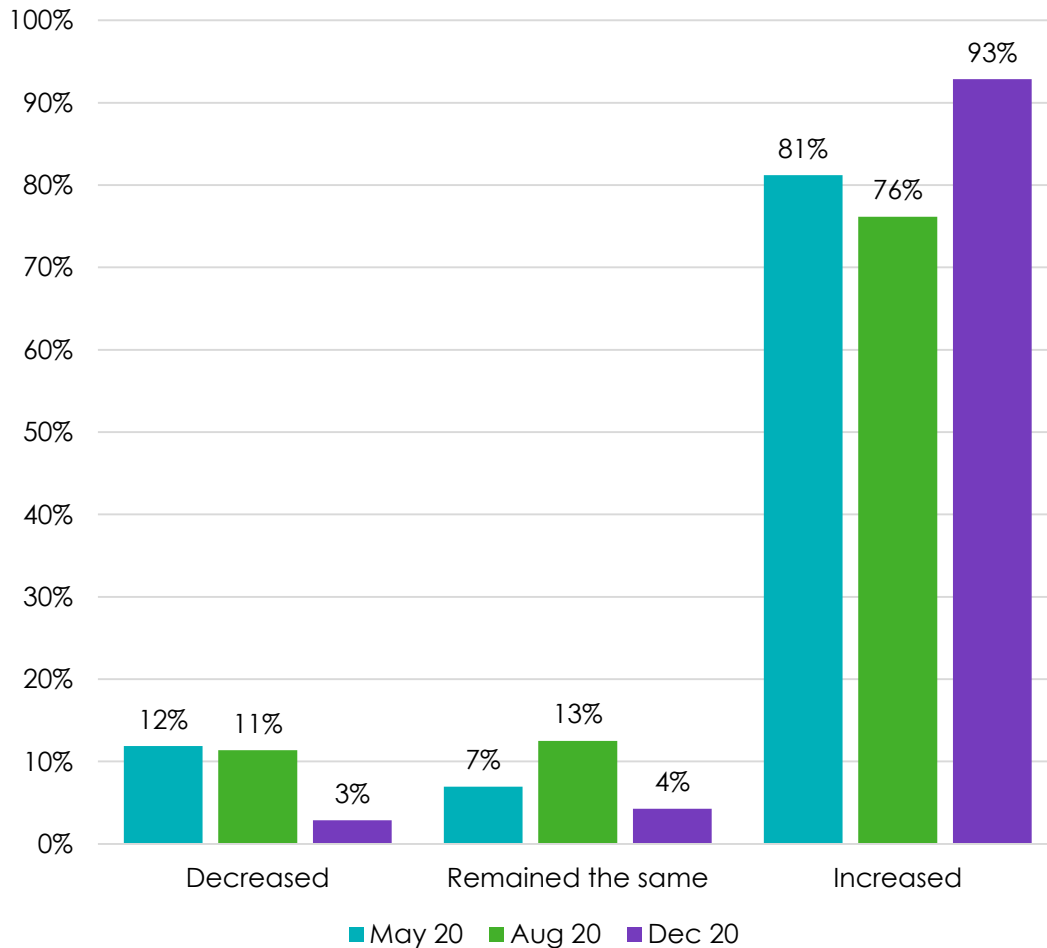
Changes in benefits, working less hours and being furloughed were the main reasons families reported reduced income levels.

These declines in income come on top of longer-term reductions in incomes for these families. Findings from our previous research showed a third of families [32%] 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 nine in 10 families [93%] reported that their household bills and costs have increased since the coronavirus outbreak.

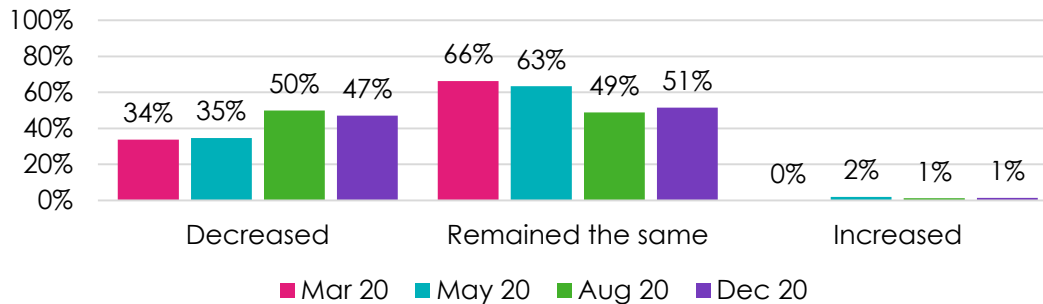
These levels show an increase on the previous waves of this research, indicating increased household costs show little signs of relenting.

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

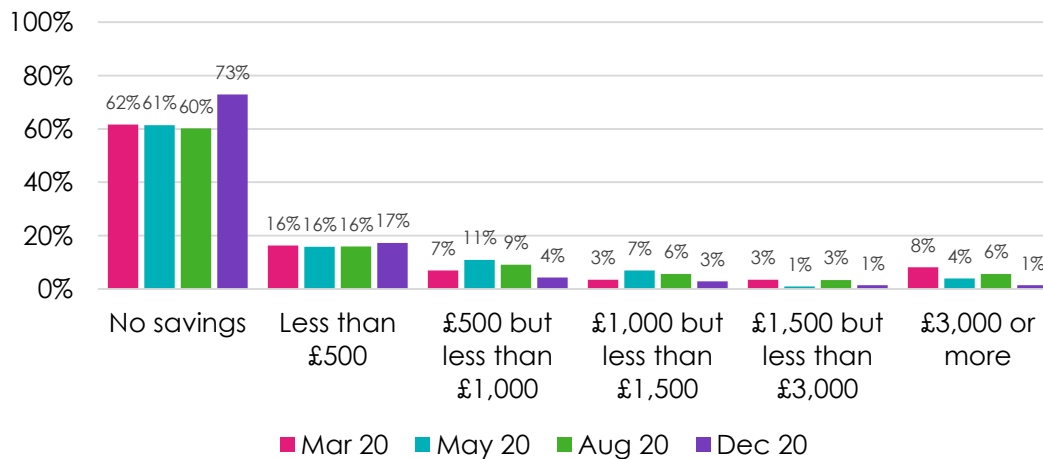


# Savings

## How have your household and personal savings and investments changed since the coronavirus outbreak?



## 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 almost half of families [47%] 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 almost three quarters of families [73%] reporting having no saving and investments.

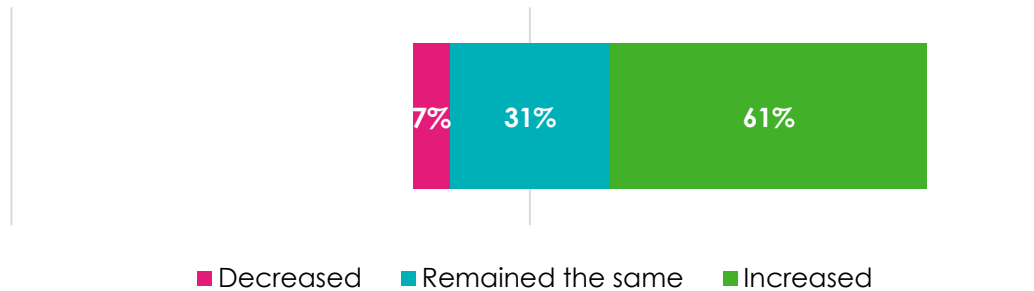
With only limited signs of improvement to the situation reported in the previous waves of research, the findings reaffirm many families raising disabled or seriously ill children are unprepared for any further sudden expenses, emergencies or continued rising costs.



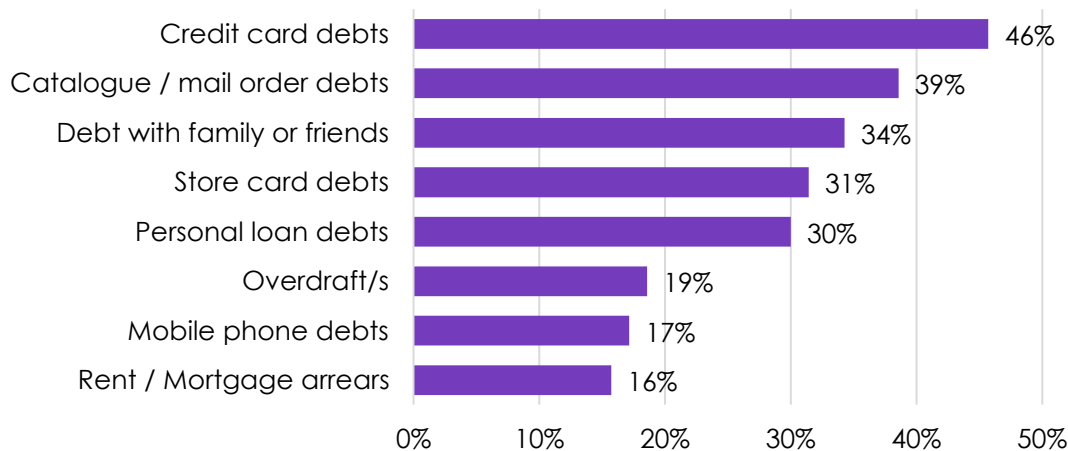


# Debts

## How have your household and personal debts changed as a result of the coronavirus outbreak?



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



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

Three in five families [61%] reported their debts have increased since the coronavirus outbreak. This is significant increase from 50% who said their debts had increased in August 2020.

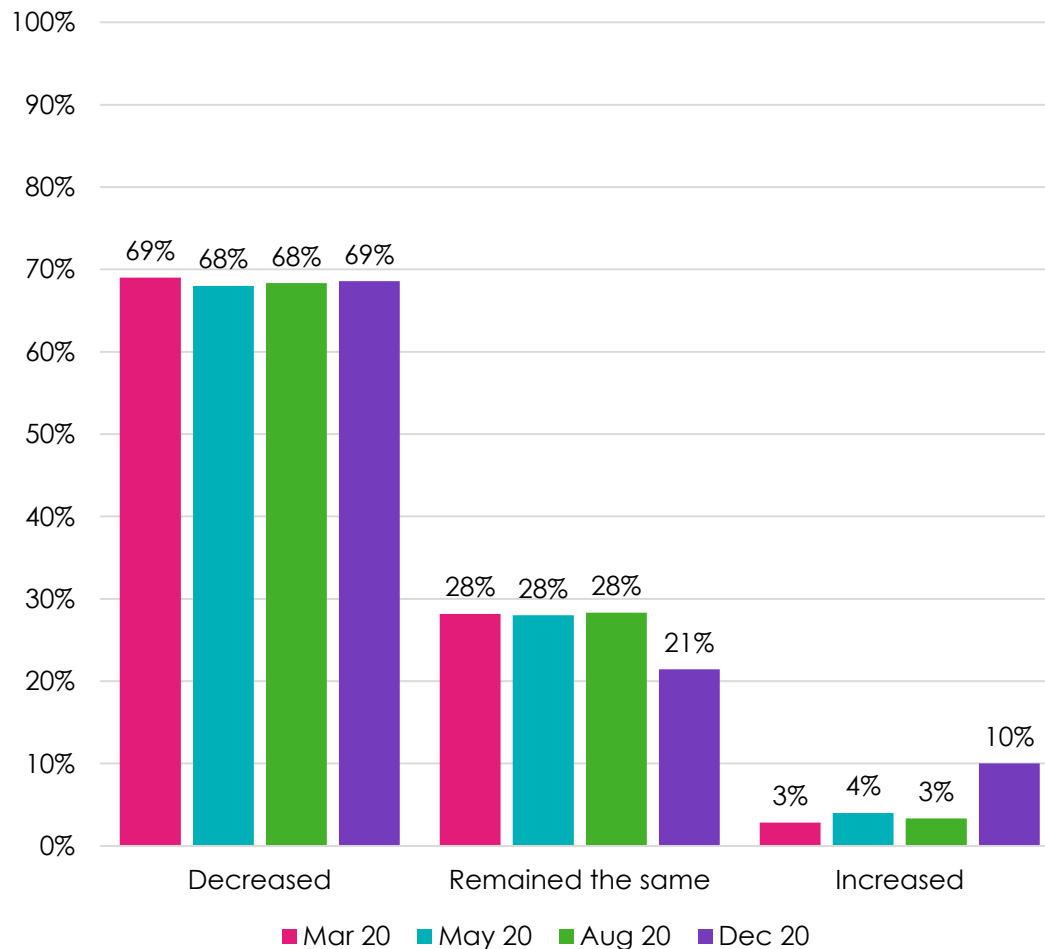
The most common debts currently held by families include credit card debts [46%], catalogue and mail order debts [39%], and debts with family and friends [34%].

Not only are the levels of debts increasing, the challenges families are facing managing these are also rising. This demonstrated by a third of families [33%] reporting them as being a heavy burden, compared to 16% in August 2020.



# 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.

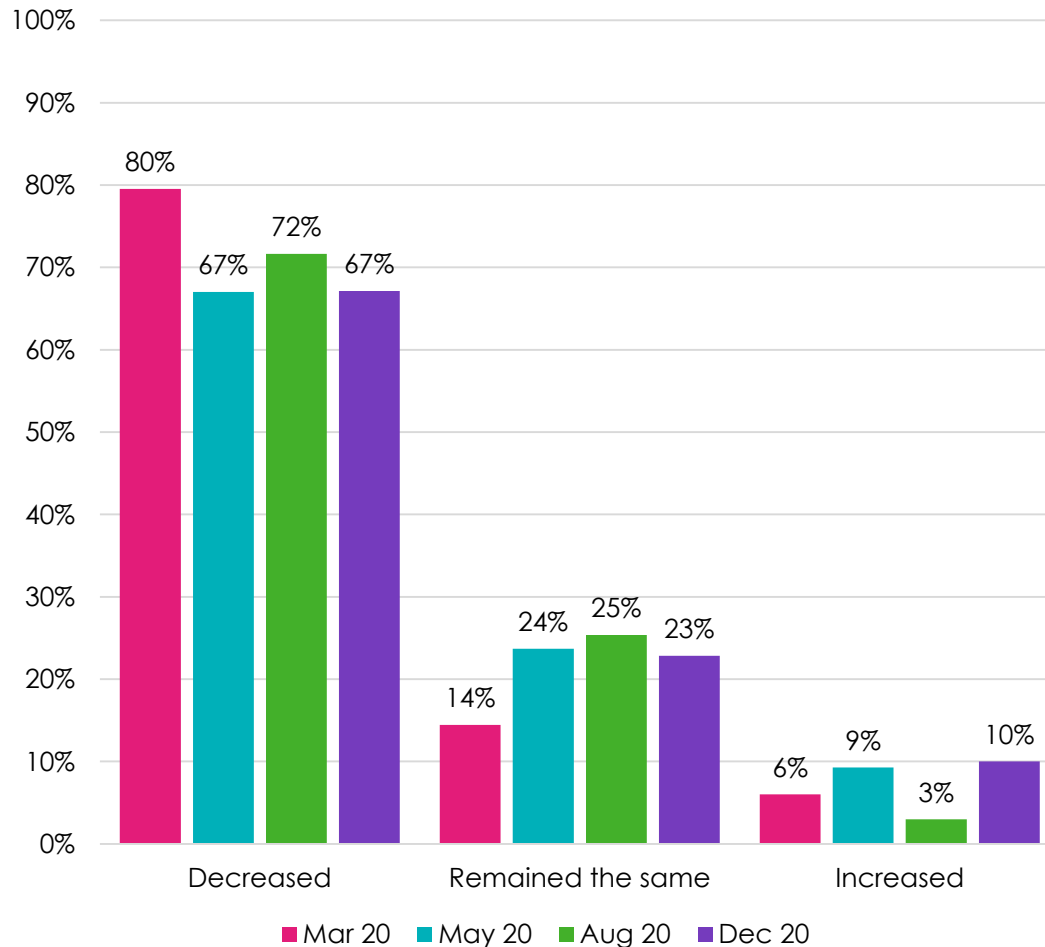
Seven in 10 [69%] are still reporting formal support for their disabled or seriously ill children have declined since the coronavirus outbreak.

The results from the latest wave of research show only a slight positive trend, but suggest progress is slow getting formal support back in place for many families raising disabled or seriously ill children.



# 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.

Two thirds of families [67%] reported the informal support available for their disabled or seriously ill children had declined as a result of the coronavirus outbreak.

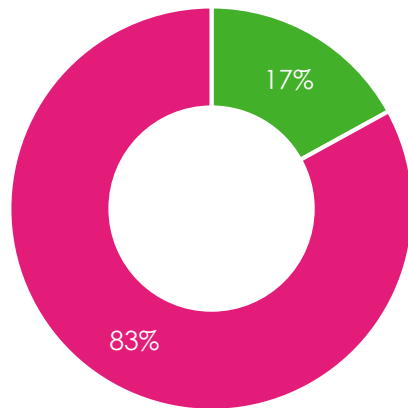
The latest wave of research shows a slight improvement on the situation reported in August 2020, however increased restrictions and lockdowns have meant many families are still going without their informal support networks.



# Education

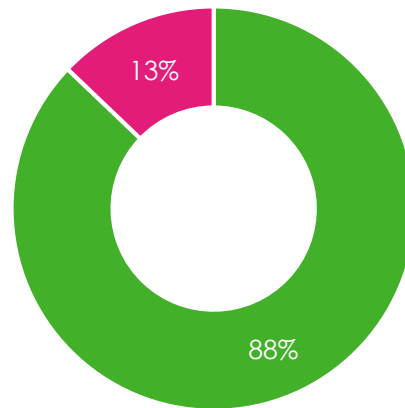
**Have your disabled or seriously ill children attended their nursery, school, college or educational hub since the coronavirus outbreak?**

Before the summer break



■ Yes ■ No

After the summer break



■ Yes ■ No

For families raising disabled or seriously ill children, their nurseries, schools and colleges can be so much more than a place of education.

For disabled or seriously ill children and young people, it is a setting in which many receive a wide range of support related to their conditions, while for parents, it can be vital respite from their caring responsibilities.

However, prior to schools returning for the autumn term, less than one in five of relevant disabled or seriously ill children [17%] had attended nursery, school or college since the coronavirus outbreak.

Since the new school year began, the numbers not attending has decreased, however more than one in 10 disabled or seriously ill children [13%] are still not attending their nursery, school or college.

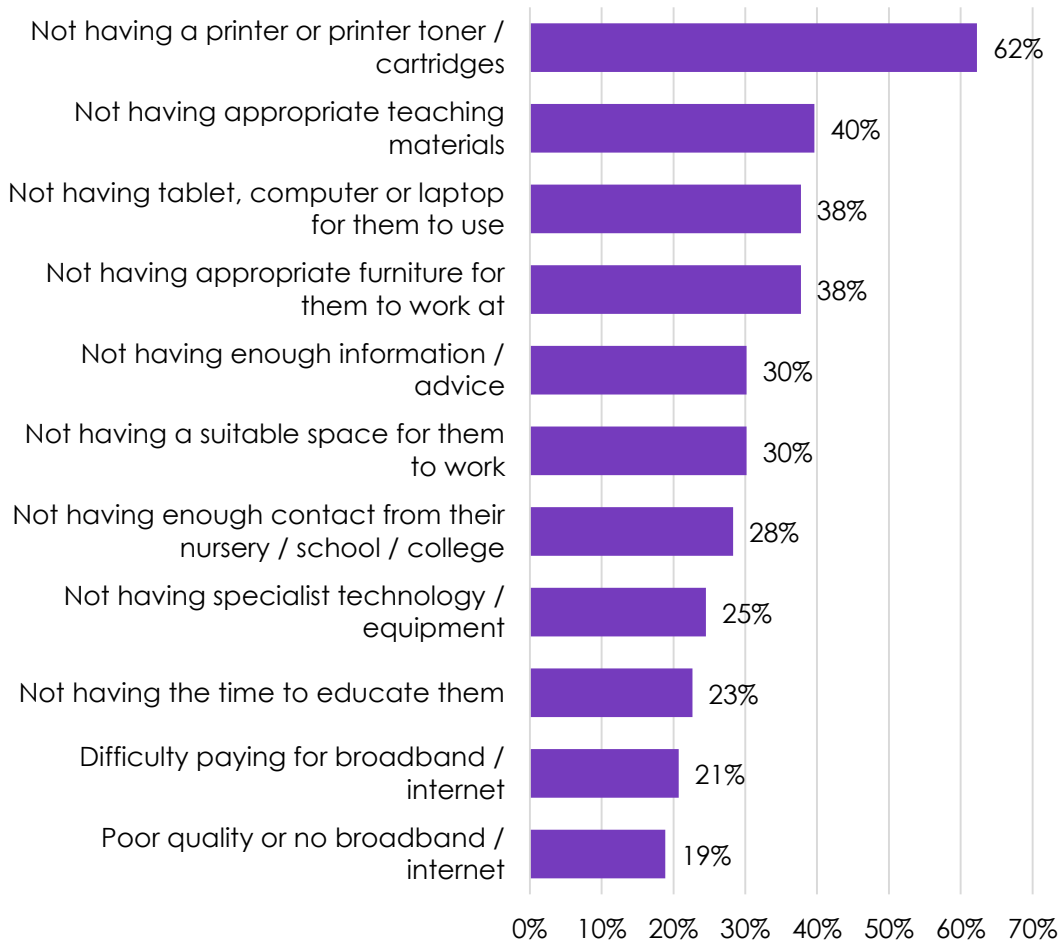
Of those attending their educational setting since the summer break, 38% of disabled or seriously ill children were attending for the whole period, and 63% were attending for some of the period.





# Education

## What, if any, barriers / difficulties have you faced educating your disabled or seriously ill child at home?



During the last year, more than four in five disabled or seriously ill children [83%] have been educated for some period at home. For many parents, this has been a challenging situation.

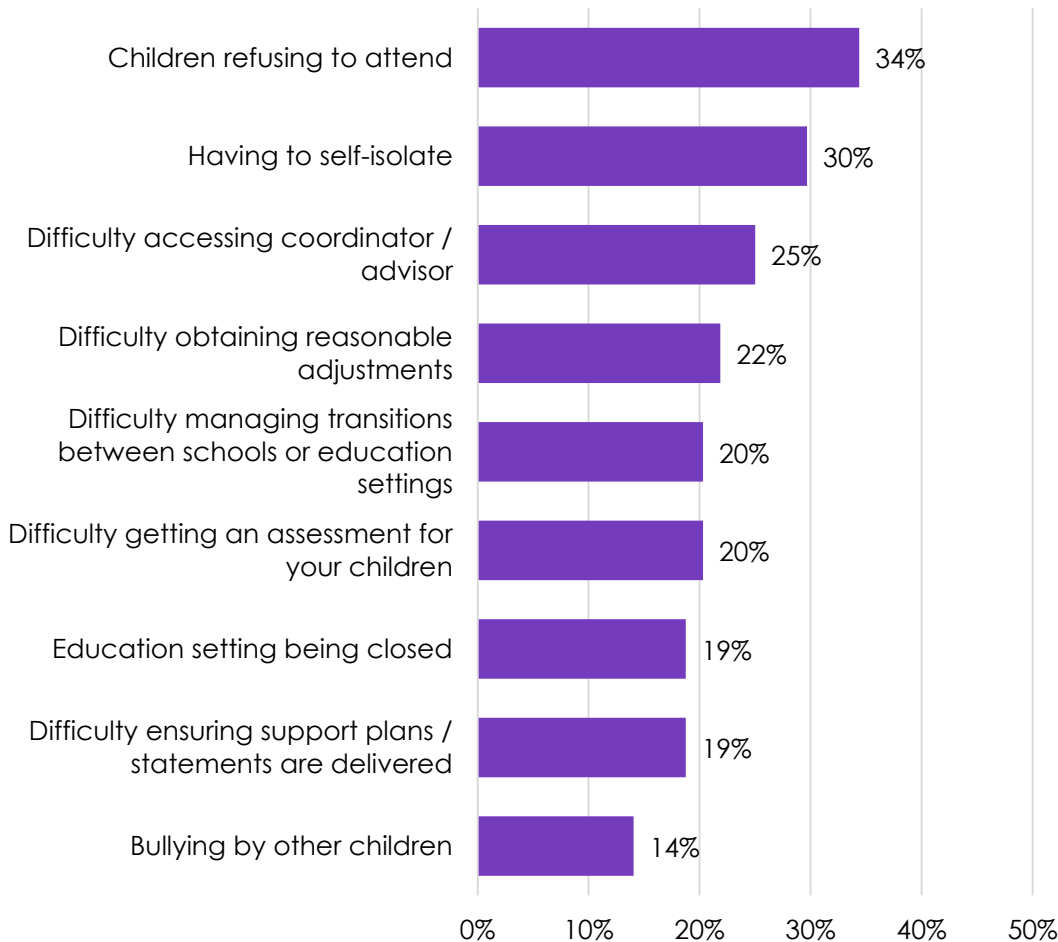
These challenges include many families lacking the items in their home to support their disabled or seriously ill children's education. This involves not having printers and printer toner [62%], digital devices [38%], furniture for them to work at [38%], specialist technology / equipment [25%], or even space for them to participate in their studies [30%].

Some of the challenges faced also relate to the support provided by schools. For two in five disabled or seriously ill children [40%] this was not having access to teaching materials appropriate to their needs. In addition, not having enough information and advice [30%], and lacking sufficient contact from their educational setting [28%] were raised as barriers to disabled or seriously ill children being educated at home.



# Education

**What, if any, difficulties have your family experienced concerning the education of your disabled or seriously ill child since the new school year?**



School anxiety or refusal continues to be a key difficulty, with this being raised for a third of disabled or seriously ill children [34%].

Having to self-isolate was identified as a common difficulty faced in disabled or seriously ill children securing an education since the new school year started. The issue of having to self-isolate was identified in relation to three in 10 disabled or seriously ill children [30%].

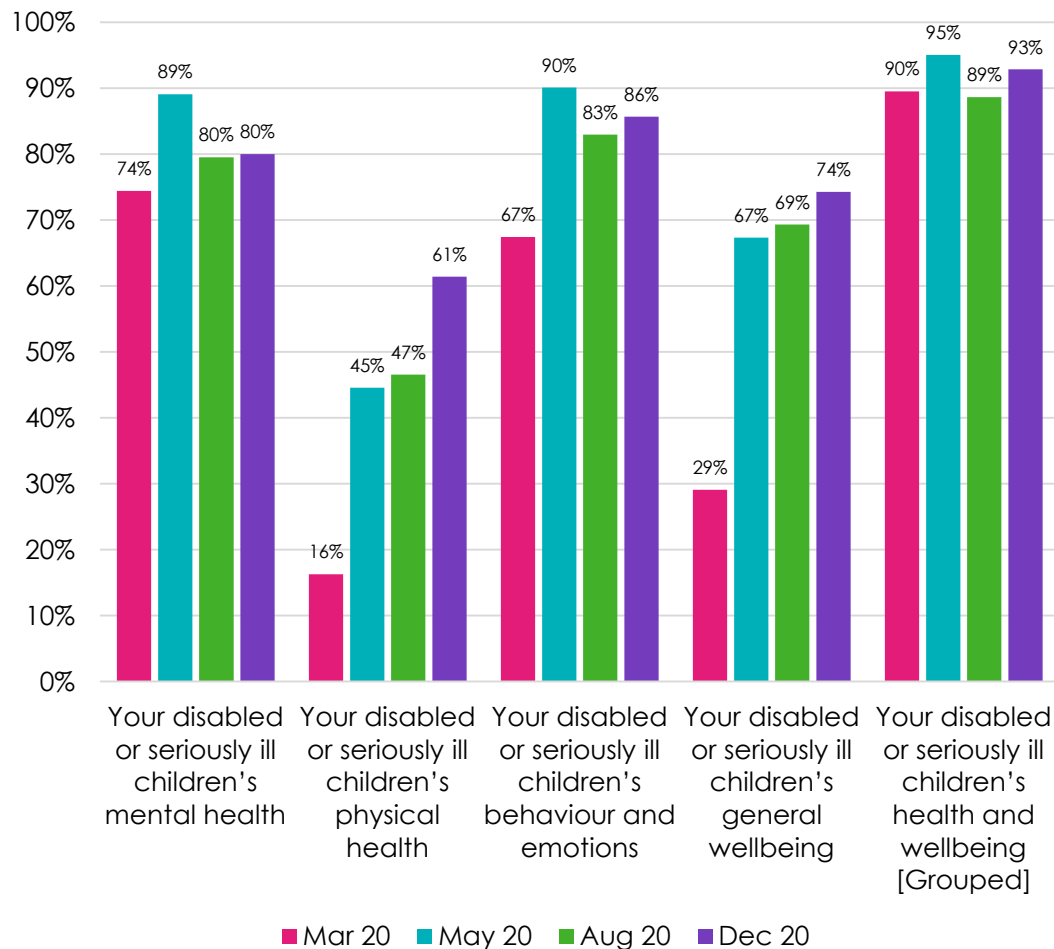
A number of the difficulties faced since returning to start of the new school year also centre around getting appropriate support. This includes accessing their coordinator or advisor [25%], making sure reasonable adjustments are in place [22%], and ensuring their support plans or statements are delivered [19%].

All this has meant many parents carers not only going without respite and taking on an increased role supporting their children's education, but also their disabled or seriously ill children missing out on support they received prior to the coronavirus outbreak.



# Health and wellbeing

Has the coronavirus outbreak negatively impacted 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 has negatively affected their disabled or seriously ill children's health and wellbeing.

In particular, families are reporting this is negatively affecting their disabled or seriously ill children's behaviour and emotions [86%], and their mental health [80%].

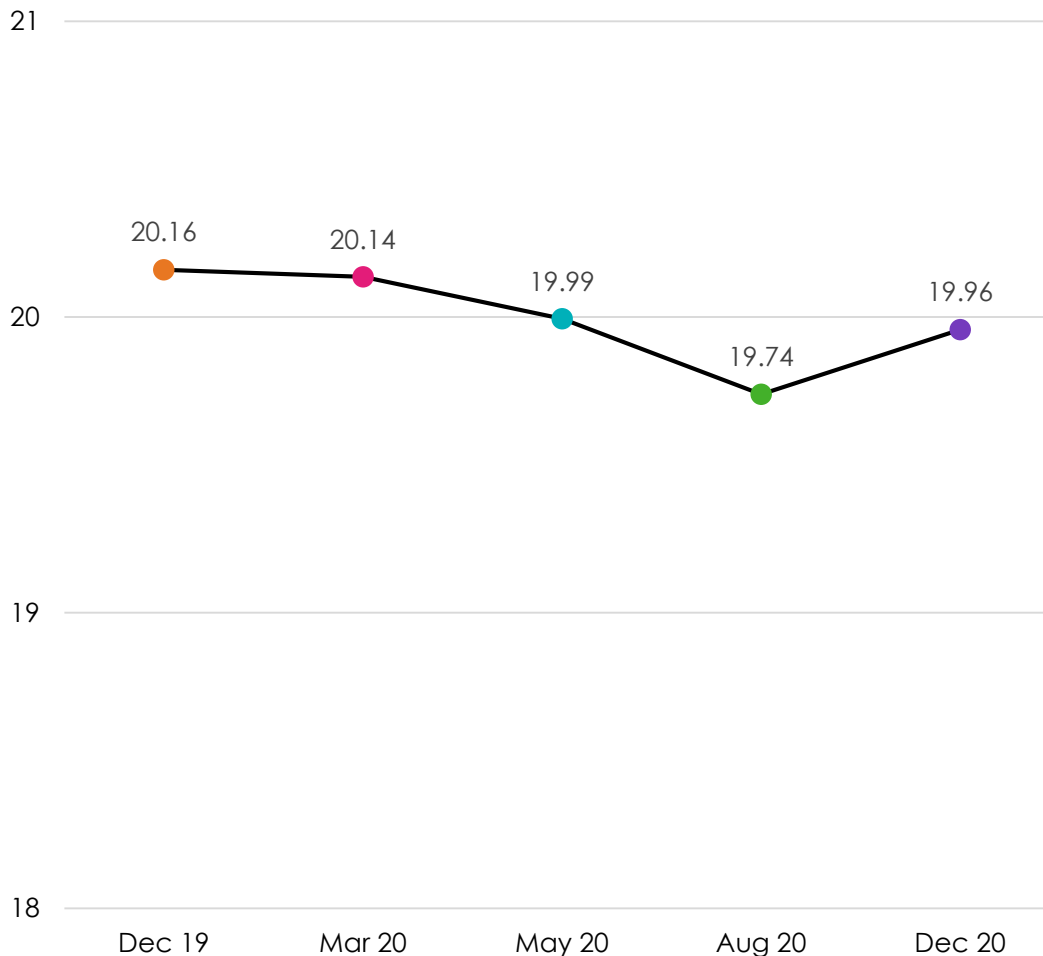
This includes their disabled or seriously ill children feeling increasingly anxious and stressed, becoming upset and experiencing more regular mood swings, as well as escalating challenging behaviour.

The research also shows significant increases on the impact on disabled or seriously ill children's physical health and general wellbeing.



# Health and wellbeing

## Warwick Edinburgh Mental Wellbeing Scale Score



As well as the impact on their disabled or seriously ill children, the research also indicates a negative affect on the health and wellbeing of parent carers.

The shortened Warwick Edinburgh Mental Wellbeing Scale has been 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 19.96. 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.

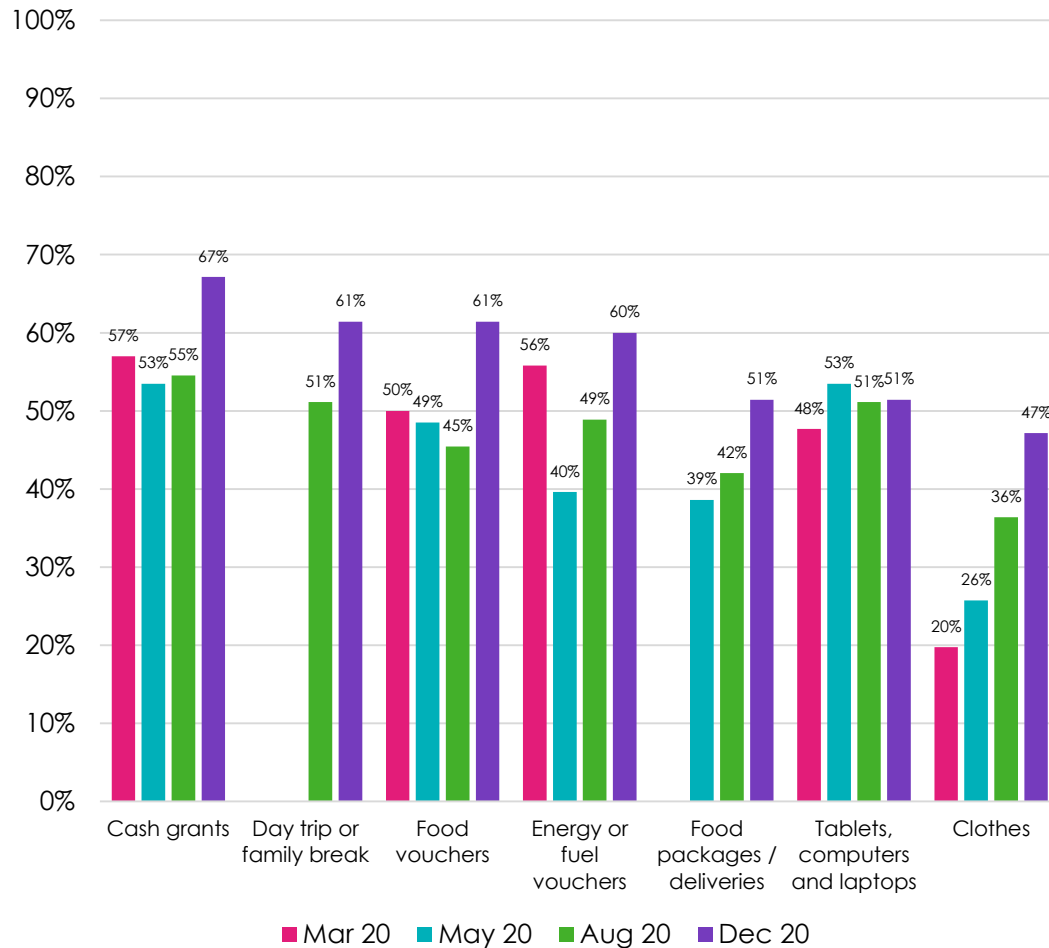
Despite signs of recovery, the evidence suggests the mental wellbeing of parent carers has not yet returned to pre-coronavirus levels.





# Needs

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



Since the early period of the coronavirus outbreak, families are increasingly saying they need things that can help resolve the day-to-day and growing financial pressures many are facing. This includes cash grants [67%], food vouchers [61%] and energy and fuel vouchers [60%].

The ongoing lack of respite or breaks from their day-to-day caring responsibilities, are also reflected in the grants families felt would be most helpful right now, with three in five [61%] prioritising day trips or breaks.

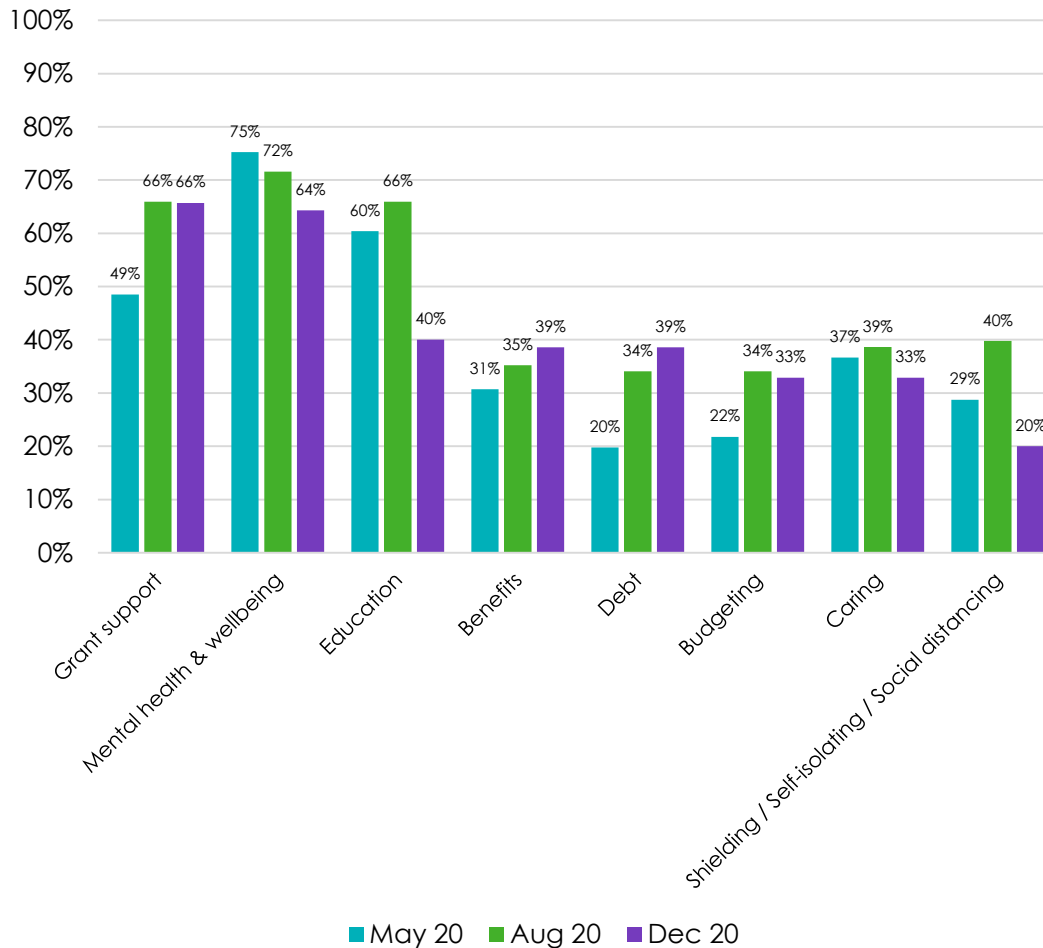
The need for digital devices continues to be important among families, with half [51%] reporting these would be helpful right now.

Clothing has also risen in families' needs, with almost half [47%] saying this would be helpful right now, compared to one in five [20%] at the outset of the coronavirus outbreak.



# 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 issues arising for families are also reflected in their information and support needs.

Mental health and wellbeing was raised by more than three in five families [64%] as an information need.

In addition, the growing financial pressures facing families are also reflected through in their information and advice needs. Since early in the coronavirus outbreak, increasing numbers of families are now indicating they need grant [66%], benefits [39%], debt [39%], and budgeting [32%] information and support.

While with more disabled or seriously ill children going back to school, less families are reporting a need for information and support around education.



# Conclusions

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The latest of four waves of research conducted since the coronavirus outbreak demonstrates ongoing challenges facing families raising disabled or seriously ill children.

Even with some positive signs around income levels, for many it looks likely to be a long financial 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.

As with families' financial situation, while the latest round of research reveals some positive signs regarding the support being provided to disabled or seriously ill children, but the recovery appears to be slow, and likely to be further set back by the latest round of restrictions and lockdowns.

This combination of increasing financial pressures and ongoing difficulties accessing support appear to be combining to negatively impact on the wellbeing of families raising disabled or seriously ill children. The research suggests the negative affect the outbreak has had on the mental and emotional wellbeing of many disabled or seriously ill children, is also showing little signs of recovering.

All of this seems to suggest a long-recovery for families raising disabled or seriously ill children, which without additional support, will see them even further disadvantaged.





# Sharing our findings

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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](mailto:research@familyfund.org.uk)







# Family Fund

## Helping disabled children

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