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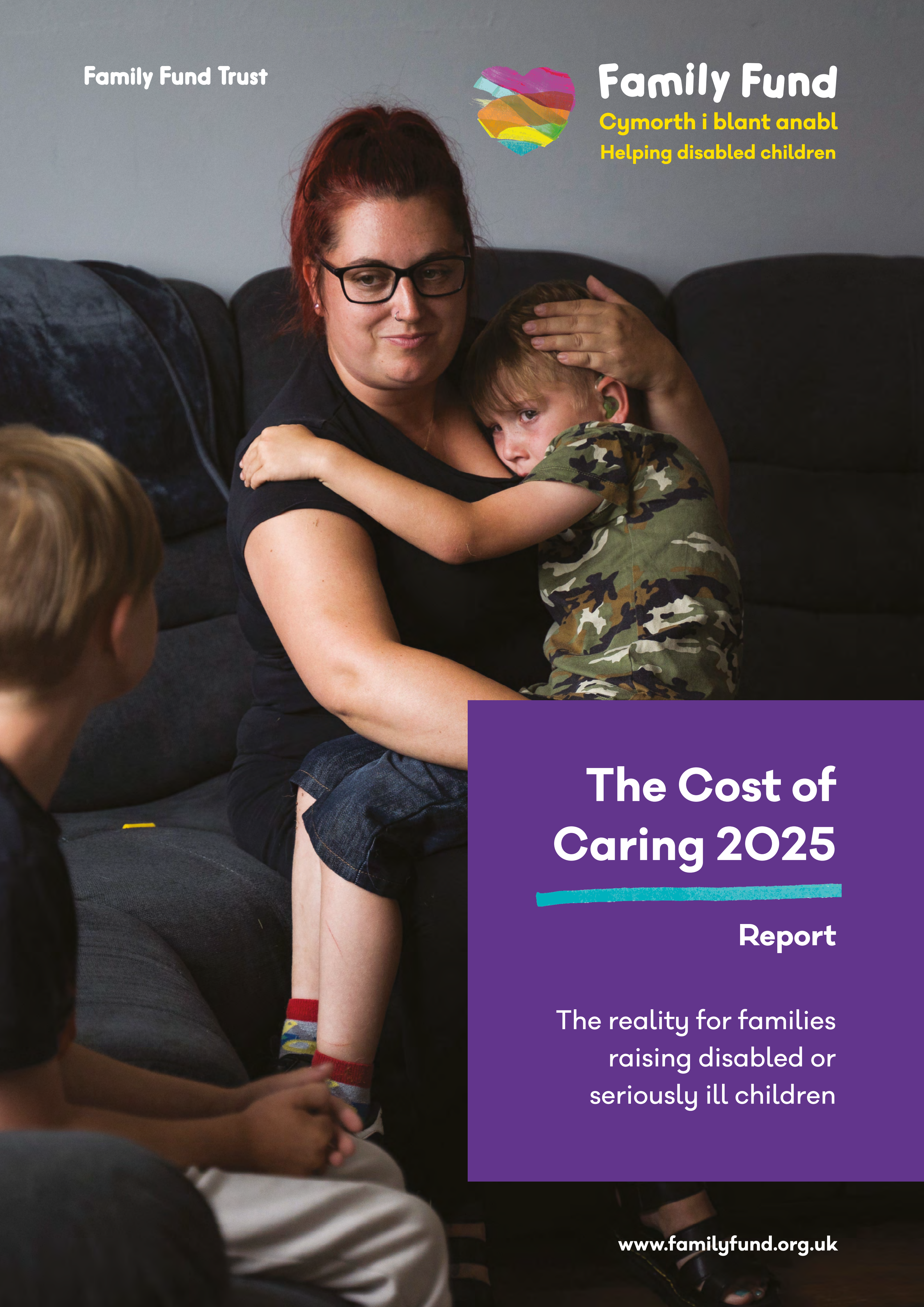

The Cost of Caring 2025

Report

The reality for families
raising disabled or
seriously ill children

www.familyfund.org.uk

The Cost of Caring 2025 - Report

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1. Executive summary

1.1 Introduction

At Family Fund, we work directly with thousands of families on a low income who are raising disabled or seriously ill children. These are families who, day after day, demonstrate extraordinary resilience but also share the reality that they are under severe financial and emotional strain.

Our latest research, *The Cost of Caring 2025*, draws on responses from more than **2,300 families** across the UK. It shows that many families struggle day-to-day, not due to poor budgeting or lack of effort, but because of the unavoidable pressures of caring and the additional costs associated with disability.

1.2 What families told us

- **44%** of families are experiencing income insufficiency, meaning they cannot meet day-to-day expenses despite receiving disability benefits.
- Parents/carers provide the equivalent of an **extra full-time unpaid caring role** every single day, leaving just **7%** able to work as much as they would like. This has a profound impact on household income and financial resilience.
- **77%** of families care for more than one disabled or seriously ill family member.
- **80%** of families are unable to replace essential household items like fridges, beds, or washing machines when they break.
- **51%** of parents/carers have had to skip meals to ensure their children can eat.
- **28%** of parents/carers have well-being scores consistent with being depressed.
- **68%** of children are negatively affected by their family's financial situation, with impacts on emotional well-being, health, development, or education.

1.3 The deeper reality behind the numbers

1.3.1 Addressing poverty through work may not be an option

For families in this research, the additional costs of disability are unavoidable with higher food bills, extra heating, specialist equipment, and increased wear and tear on the home. These costs accumulate at the same time as parents/carers are often forced to reduce or leave paid work due to intensive caring responsibilities.

> **We skip meals regularly. It's not a choice, it's survival.**

> **Even small things like replacing a broken bed or fridge are out of reach.**

Accessing suitable childcare, often seen as a solution to poverty as it enables parents/carers to maintain paid employment, is not straightforward. For children with complex needs, appropriate childcare is often unavailable, unaffordable, or unsuitable. Even where it is available, most parents/carers report that childcare alone would not enable them to increase paid work.

1.3.2 The cost of caring is emotional as well as financial

What is clear from our research is that parents/carers go to huge lengths to do the best for their children, often sacrificing their own well-being in the process. As a result, many parents/carers report exhaustion, poor mental health, and extreme loneliness.

> **"I always make sure my child has food, warmth and clothes — but I go without so they don't have to."**

> **"I just wish there was help for people like me. I am really struggling just with day to day living costs for myself and my children. It's having a massive impact on my mental health. It's becoming very overwhelming and I have no family to support."**

> **"I feel I'm failing my child and not meeting her needs because we just don't have enough money and it affects our physical and mental health. It makes me feel like such an awful parent."**

Many families are also more likely to face multiple disadvantages as they are caring not only for disabled children but often for disabled siblings, partners, or being disabled themselves. This compounds the emotional and financial strain.

1.4 Family Fund's role

As an established UK-wide charity, Family Fund provided more than 200,000 grants and instances of support to families last year. This included:

- Grants of essential items including household goods, specialist equipment and family breaks.
- Practical advice on maximising income and navigating digital barriers
- Trusted, flexible, and family-centred support at critical moments.

We see firsthand the huge difference this support makes - reducing stress, preventing family breakdown and helping children thrive.

1.5 What needs to change

Our research demonstrates that:

1. **The additional costs of disability – both financial and emotional - must be properly recognised** in the support available to families.
2. **Policy** must take into account that, for many families, increasing paid work is not a viable solution to poverty.
3. **Childcare and respite** services must be available, affordable, and tailored to children with complex needs.
4. The **well-being of carers** must be prioritised. Without this, families risk reaching crisis point, with long-term social and economic consequences.

1.6 The call to action

Families are doing all they can, but they need support that reflects the complexity of their lives.

We call upon policy-makers, funders, support agencies and charities to recognise the day-to-day realities faced by families, and work together to create a fair and sustainable future for families on a low income, who are raising disabled and seriously ill children.

No family should have to choose between heating, eating, and caring for their child.

2. The financial cost of caring

2.1 Disability costs more – and families feel . the impact every day

> **“I stay awake worrying about how I will afford to pay everything and keep everyone fed and warm.”**

> **“My daughter’s sensory needs have increased leading to more broken furniture, damage to the property, damage to her clothes and constant need of sensory resources.”**

> **“The money we get for my son’s disability is what we are using to pay most of the bills and this is making our day to day living expenses difficult.”**

Food to eat, a bed to sleep in, clothes to wear, and a warm, safe home. These are not luxuries. They are “the basics” that all parents strive to provide for their children. But for families raising a disabled or seriously ill child, covering these basics comes with a higher price tag.

- Children may need to follow a special diet, or take more meals at home - so the weekly food bill costs more.
- A child may need a bed that provides a higher level of support due to their physical condition. Higher specification beds and mattresses are available – but they are more expensive.
- Bedding may need to be changed more frequently, which means having more of it.
- Some conditions mean a higher level of wear and tear on clothing. This means buying more clothes, more often. Other conditions cause tactile sensitivity, which means buying specially-made clothing – available, but at a higher price.
- The home may need more heating or cleaning to ensure children avoid infections that could have a dangerous impact on health. Turning the heating off is not an option, and extra cleaning products add to the cost of the weekly shop.

It all adds up. And disturbingly, for families on a low income, it often adds up to more than the family can afford.

Our Poll once again confirmed that parents/carers with disabled children pay more for the day-to-day essentials.

- 99% of parents/carers report having to pay more for everyday essentials
- 77% of parents/carers report spending more on food that they otherwise would
- 76% of parents/carers have to spend more on clothing for their child
- 60% have to spend more on bedding
- 48% spend more on cleaning products

Added to this, 78% of parents and carers say they regularly have to find money to buy specialist items for their child.

The additional cost of disability is widely acknowledged and benefits such as Disability Living Allowance, the Personal Independence Payment, and the Child Disability Payment (in Scotland) are there to address it. Recent uplifts in benefits have had a positive impact, but many families are still experiencing a significant shortfall.

2.2 There isn't an adequate financial safety . net for families raising disabled children

> **"I try to focus on paying all my household bills but if something big has to be replaced it becomes more difficult to juggle things to cover the cost. A few weeks ago my oven and fridge broke around the same time and I had to borrow from family."**

The higher cost of day-to-day living means that many families raising a disabled child are living without any financial buffer. With nothing to fall back on, even a small, unexpected cost, such as a broken appliance, or a family emergency, can be unmanageable. As a result, many families have no option but to go without essential household items.

Our Poll found that:

- 87% of parents/carers have no savings at all
- An additional 5% have savings of less than £500
- 38% said they could not afford an unexpected expense of just £200

2.3 Parents/carers are forced to go into debt, just to keep the family going

> **“I use my Pay-In-3 on my PayPal or ClearPay. My mum helps me massively. If something goes, she would borrow me the money and I pay her back.”**

For many families in our Poll, debt is not a choice. It is an unavoidable fact of life.

Parents/carers who responded to our Poll painted a picture of families who are constantly having to juggle household finances, and who make ends meet by going into debt or relying on support from other close family members. Worryingly, a significant number of families reported that they rely on credit to cover regular household expenses because the higher costs of caring for their disabled child(ren) are placing too much strain on the family’s finances.

Our Poll found that:

- 83% of parents/carers say they are in debt
- Of those, 83% are struggling to keep up with repayments
- 57% expect to go further into debit in the next six months
- 43% are behind on essential household bills
- 38% have used credit to pay essential bills
- 33% have used credit just to get through to the next payday or benefits payment

2.4 Doing without has become a way of life

> **My kids had miss clubs as I had no money for travel. I couldn't buy them new pjs when they had grown.**

> **We've never been on holiday and rarely have a day out.**

For families with disabled and seriously ill children, making memories, sharing special times together, and taking time to play and have fun is extremely important. This doesn't always require money, but having a little to spare for treats like presents or days out can be the difference between enjoying life and just getting by.

For many of the families responding to our Poll, family finances often do not stretch to cover the every day essentials, leaving "extras" completely out of reach. Our Poll findings painted a grim picture of families whose financial constraints mean that doing without has become a way of life, with little or no chance of change.

- 74% of parents/carers say that family breaks are unaffordable
- For 22% of families, celebrations for birthdays or Christmas are something they have to do without
- One in ten parents/carers report they are unable to buy a winter coat for their children
- Almost one quarter of the children have no access to play equipment such as a bicycle or digital devices

2.5 Work doesn't work for many parents and carers of disabled children

Moving from benefits to paid work can be an effective way out of income insufficiency for some, but it is not viable for all. For many parents/carers of disabled and seriously ill children, there are significant practical barriers that prevent them from taking up opportunities for paid employment.

2.5.1 The complex pattern of disability and caring can prevent paid employment

> **"We are all registered disabled in my household, and I deal with my two mentally disabled children alone."**

> **"(My) husband is self employed and when I have been in hospital (which is often and prolonged) he cannot work. Therefore we have no income."**

> **"I am also a carer for my elderly severely disabled mother and father."**

Caring for a child with complex needs can be challenging both financially and emotionally, but for many of the families in our Poll, this is not the whole story. For many, family life is shaped by complex layers of disability and care, sometimes spanning generations and households. The level of caring responsibilities, and the commitment and energy this requires, can have a profound impact on the choices open to the family, and in particular the ability to undertake paid work to support the family's finances.

Our Poll discovered that:

- Only 15% of parents/carers responding to the survey say that their only experience of disability in their household is the child supported by a Family Fund grant
- 77% of families report multiple disabled people in the household
- An additional 4% report caring responsibilities for people outside their immediate household
- More than half of the parent/carers who responded to our Poll said they themselves are disabled.

2.5.2 Caring commitments do not easily combine with paid employment

> **"Please stop trying to force exhausted carers into work. We need to be paid and valued for the unpaid work we do looking after our children! I cannot work, and would be far too exhausted to work even if this was an option."**

> **Some days my child is fine in school. Other days I need to go up a few times to either hand things in for him or to collect him as he can't be calmed down. It makes it hard when applying for jobs as I can't guarantee the hours.**

> **I don't think I can work at all until the children are older and more able to support themselves. I have to be on call to collect them when they are at school. I'm constantly taking phone calls from hospitals, doing admin tasks to support them, have them home sick, taking them to hospital and doctors' appointments. There is no employer that would allow me to take the time needed to care for the children.**

On top of the usual parenting time, disabled and seriously ill children can require several hours of extra support every day for personal care, supervision, medication and therapies and medical appointments. This often leaves parents/carers exhausted, with little or no time and energy to take on paid work.

Added to this, the unpredictability of care makes it difficult for parents/carers to accommodate paid work regularly into their day, putting them in the untenable position of having to choose between an employer's need for reliability and the child's need for immediate parental support. In practice, parents/carers put the needs of the disabled child first, meaning that opportunities to increase income through paid work must be set aside.

2.5.3 Lack of suitable childcare

> **“(I need) afterschool care and holiday club which is suitable for my child’s needs. Currently on the waiting list for the only facility in our area and have been on this waiting list for five years.”**

> **“Having access to a more flexible / greater variety of childcare options would change mine and my child’s life. For example being able to employ a nanny who isn’t Ofsted registered to look after my child at home would mean I could have someone to look after my child after school and during school holidays whilst I work.”**

Family, friends and registered child-carers are all important providers of care and support to families raising disabled and seriously ill children. However, when it comes to formal childcare provision, parents/carers report it can be difficult or impossible to find suitable placements, especially for children with complex emotional and behavioural or medical needs.

According to our Family Poll:

- 29% of parents/carers believe better access to childcare would enable them to work more
- 41% parent/carers say cannot access as much formal childcare as they would like
- 37% are unable to access as much respite care as they would like
- 39% are unable to access as much childcare from friends and family as they would like

Awareness of support for childcare via Universal Credit and tax-free subsidy was strong (two thirds of parents/carers are aware of their options and 26% say they are using at least one of these schemes). However, parents/carers report some barriers to access, as the requirement for childcare providers to be Ofsted-rated means that availability is very limited. As a result, parents/carers are having to use Universal Credit or the tax-free childcare subsidy on personal assistants to care for their child in their own home.

2.5.4 Lack of trust in childcare provision

> **"I would not leave my son with childcare companies as he is non-verbal and vulnerable."**

> **"Unfortunately our last childcare/respite broke down as children didn't feel safe there."**

> **"No family or friends feel comfortable to watch Archie…, so he is only in our care."**

Unsurprisingly, given a steady stream of high-profile cases concerning abuse of children and young people in formal settings, parent/carers do not always feel able to trust care providers to meet their children's needs. Even when parent/carers feel able to trust a provider of care, these placements sometimes break down as the children and young people themselves did not feel safe.

In addition to this, at times due to the complexity of their child's needs, many parents/carers did not feel able to draw from their wider social circle outside the family home.

According to our Family Poll:

- 55% of parents/carers are not interested in childcare from family and friends who they do not live with
- 62% do not feel improved childcare access would enable them to work more hours

From the responses to our Poll, it is clear that many parents/carers feel that the duty of care rests solely on them and is the best – and often only – safe and reliable option for their child. In such circumstances, taking up paid employment becomes a choice that can only be achieved at the expense of their child's welfare.

2.5.5 The benefit cliff edge makes work not financially worthwhile

> **“I completed an eight-month course to earn more at work. It meant I worked 37.5 hours per week and then studied 20 hours per week at night when my daughter was asleep. I earned only slightly more and lost most of my Universal Credit. I’m doing my best to get to a point where we can live feeling safe in the comfort of our home.”**

Parent/carers who do work say cliff edges in the benefit system can mean that they are often worse off or only marginally better off by working. When the challenges of childcare are also factored into the equation, following the route of paid employment becomes an almost unsurmountable challenge for some families.

3. The human cost of caring

3.1 Parents/carers are shielding their disabled children at their own expense

> **“As a parent I have skipped meals so my son can eat.”**

> **“My husband and I go with less to provide to limit any impact on the children. Spending less on ourselves means we can stay above board and not go into deficit.”**

Over many years of supporting families, Family Fund has seen how parents and carers put their children’s needs first, and the findings of this year’s Family Poll are no exception. The responses to the Poll clearly show that parents and carers are shielding their disabled children from the impact of income insufficiency by putting their children’s needs ahead of their own – even at the expense of their general health and well-being.

Our Poll revealed that:

- 46% of parent/carers cannot afford necessary dental treatment
- 25% are cutting back on their own bathing
- 17% are unable to afford over the counter or prescription medication for themselves
- 11% are unable to afford toiletries such as toothpaste for themselves

3.2 Disabled children in low-income house holds face a “double disadvantage”

Notwithstanding the efforts of parents and carers to shield their children as best they can, a worryingly high proportion express the view that income insufficiency is having a broad, negative impact on their children’s lives, and even on their development.

According to our Poll:

- 68% of parents/carers felt that their financial situation was impacting on one or more aspects of their child’s well-being and development
- 25% of parents/carers said that **all** areas of well-being and development were being hit
- 62% said that emotional well-being was affected
- 34% said that physical growth and development was affected
- 39% said that their child’s ability to engage with education was affected
- 39% said that their child’s health, including conditions that are part of their disability or illness were affected

From our findings, it is apparent that disabled and seriously ill children and young people are facing a “double disadvantage” from the combined impact of their condition and the impact of limited family income – with one often being the consequence of the other.

3.3 Carers need care themselves – but often struggle to find it

> **"It's really hard going month to month, pay to pay. I don't know one special needs parent without mental health issues. It's down to the lack of help and funding we get. It's like we choose to have a child with additional needs. Really unfair and hard."**

> **"I am a single mum. I have my own health issues and cannot work. Looking after a disabled child is hard. I was going to put in for PIP for myself, but I get Carers Allowance and don't know what I would need to do."**

> **"Husband had to give up his full-time job earlier in the year as it was too stressful with looking after the children. This had a huge financial impact on the family for seven months as both of us were on Carers Allowance, therefore a very low income. This caused strain on family relations."**

There is no doubt that caring for a disabled child costs more in pounds and pence, but our Poll also strikingly highlights the emotional cost paid by many parents and carers, who face complex pressures that can seem almost impossible to escape.

- When assessed via the validated Short Warwick Edinburgh Mental Well-being Scale, 28% of parents/carers who responded to our Family Poll reported their mental well-being as low enough to indicate clinical depression
- Many also feel incredibly lonely. When assessed using the UCLA Loneliness measure, 26% reported a maximum score.

Time may well be an important factor here. The time required to care for a child with complex needs can be great, leaving little time for other things. This can isolate parents/carers from friends and family and make it difficult to seek out and take advantage of the help and support that is available to them. As a result, stressed parents/carers can become locked into a relentless regime of care that provides little opportunity for them to rest and recharge or explore options for help and change.

4. Recommendations

Family Fund has more than fifty years of experience in supporting families on a low-income who are raising disabled and seriously ill children. Through our Family Poll, we give voice to families who are at the sharpest edge of income insecurity, yet too often invisible in broader conversations about child poverty, benefits, support provision and employment opportunities.

Our findings demonstrate that any strategy seeking to address these issues must:

- Understand the real-world complexity of these households
- Recognise the layered burden of care and financial stress
- Create and sustain meaningful solutions – benefits, hardship grants, employment support, community-based programmes, childcare and wider services – that are easy to access and that target the specific issues faced by families
- Address the "double disadvantage" of disability and poverty that is the day-to-day reality for the families in our Poll, and the many thousands more who experience similar issues

Built on our findings, we recommend the following.

4.1 Grant support for essential needs

The disability premium leads to income insufficiency, where families cannot pay for their essential needs and saving even small amounts for larger items is impossible. Whilst benefits keep families afloat, grant support can be a particularly helpful way to give families access to necessary items that benefits will not cover. However, the provision of grant support through local authorities is uneven, and often hard for families with caring responsibilities to access, whilst support through the third sector is often dependent on short-term funding, leaving families at risk of losing a lifeline.

We recommend: that investment be prioritized into targeted, sustainable and easy-access grant support, that is available to families raising disabled and seriously ill children at the point of need. The ability to access grant support will prevent more families falling into debt or financial crisis and alleviate pressures on local services.

4.2 Flexible back to work support

Families raising disabled or seriously ill children or young people have multi-faceted caring responsibilities. Many parent/carers are themselves disabled and can have limited capacity to work because of their own health issues. The provision of childcare and workplace support does not adequately address the needs of parents/carers with significant caring responsibilities.

We recommend: that support to help carers back into work is designed to address this complex mix. Interventions should holistically address care for children and young people, and incorporate workplace support for disabled adults. Solutions require a flexible approach that recognises capacity to work can vary, often at short notice.

4.3 More research on childcare

Only a minority of families would find better access to childcare an enabler to taking more paid work. This may reflect widespread concerns about the availability and suitability of current childcare options. Whilst current policy initiatives seek to address these issues to a degree, best practice is not universal. In particular, some parent/carers suggest care for their children may be provided more effectively by social carers in the child's own home than in Ofsted registered placements (the only ones available when funded via Universal Credit or Tax Free Childcare). Parent/carers would welcome consideration of the feasibility of this.

We recommend: better evidence should be gathered on how to meet the needs of disabled children and young people with appropriate and accessible wrap-around childcare, including the provision of high-quality home-based care.

4.4 Prioritising the relief of carer stress

With many parents and carers close to burnout, support should go beyond an offer of alternative care and focus on their ongoing well-being. Support provision should respect that parents/carers may prefer to care for their child themselves – and this may be the best option for the child.

We recommend: prioritizing support to relieve carer stress by enabling carers to rest and recharge, and families to spend quality time together. For example, this could include expanding provision of carer and family breaks such as those provided by Family Fund.

5. Research methodology

The data for The Cost of Caring 2025 was drawn from Family Fund's Family Poll in December 2024. The Family Poll has been produced by Family Fund annually for many years to provide insight into day-to-day realities faced by families raising disabled or seriously ill children.

Invitations to participate in the Family Poll were issued to 26,159 parents/carers on 3 December 2024. Those invited to participate included:

Parents/carers with a valid email address who had received a grant in the previous nine to twelve months from one of the following grant programmes, which are focused on families on a low income raising a disabled or seriously ill child with significant support needs:

- The Support for Families with Disabled Children (SFDC) programme, which is funded by the Department for Education in England, and administered by Family Fund
- Family Fund's grant programme in Wales, funded by the Social Services & Integration Directorate of the Welsh Government
- Family Fund's grant programme in Scotland, funded by the Directorate for Children and Families of the Scottish Government
- Family fund's grant programme in Northern Ireland, which is funded by the Department of Health of the NI Executive.

Parents/carers who had opted out of further contact from Family Fund, or who had notified us of a bereavement were not included in the invitation.

Data collection closed on 13 December 2024.

2,362 responses were received. These comprised:

- 1,710 responses from parents/carers in England (9% of 19,175 invited to take part)
- 232 responses from parents/carers in Scotland (10% of 2,293 invited to take part)
- 145 responses from parents/carers in Wales (8% of 1,785 invited to take part)
- 266 responses from families in Northern Ireland (9% of 2,906 invited to take part)

Of those who responded:

- 99% of respondents were solely or jointly the main carer
- 41% of parent/carers were lone parent/carers
- 98% were the parent of the disabled or seriously ill child or young person, with a further 1% grandparents/carers or other relatives.
- 19% identified as being from a minority ethnic group.
- 49% of respondents were aged between 35-44.
- 95% of respondents were female.

Responses to the Family Poll were analysed by Family Fund's Research Team in the early part of 2025, led by Dr Abigail Dunn, Head of Policy, Research and Evaluation. The Research Team noted that parent/carers chose if they wished to respond and therefore there are likely to be hidden structural biases that affected that decision. For example, working parent/carers may be underrepresented in the findings due to limited time to participate in the Poll.

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