

Scottish Parliament Social Justice and Social Security Committee

Post Legislative Scrutiny of the Child Poverty (Scotland) Act 2017

Written submission by National Carer Organisations, September 2024

Introduction

The National Carer Organisations welcome the opportunity to submit a response to the Scottish Parliament's Social Justice and Social Security Committee's call for views to Post Legislative Scrutiny of the Child Poverty (Scotland) Act 2017.

The National Carer Organisations are Carers Trust Scotland, Carers Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all of Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The National Carer Organisations aim to achieve this through the representation of unpaid carers and amplifying their voices at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

Consultation questions and response

1. The Act introduced a statutory framework for reducing child poverty. What difference has that framework made to the way the Scottish Government has approached reducing child poverty?

The Child Poverty (Scotland) Act 2017 sets out statutory targets to reduce relative child poverty, these targets are legally binding and ensure more accountability from Scottish Government. Child poverty targets, delivery plans and reporting requirements are underpinned by the legislative framework in the Act.

The Child Poverty (Scotland) Act requires Scottish Ministers to produce child poverty delivery plans every four years with updates on progress annually. The framework has led to a more strategic approach and Scottish Government have introduced benefits such as the Scottish Child Payment, Best Start Grant and Best Start Foods to help provide financial support. However, there still continues to be

barriers for low-income families, such as the two-child limit on Universal Credit and school holiday childcare, which limits employment opportunities.

"More wrap around care for disabled children [is needed]. Normal school hours is not long enough days for childcare for my area of work. There is a definite gap for specialist/ increased support in wraparound care for before/after school club for children with ASN." (Carer, State of Caring 2023)

"There are activities I take my disabled children to where I could pay to join in but I can't afford it. I've leisure and sports. Carers often don't count for discounted

prices.” (Carer, State of Caring 2023)

Within this response, the National Carer Organisations highlight particular areas where we believe there is insufficient coordinated action to address the many challenges they face, leading to sustained poverty for children, young people and families. This section focuses on families with caring responsibilities and young carers.

Families with a disabled adult or child

Whilst there is priority given to these groups, it is unclear whether there is sufficient cross governmental scrutiny of actions and their outcomes for these families, nor sufficiency of investment to address the poverty they experience.

Carers Scotland’s State of Caring reports in 2023 gathered data from parents with a disabled child under 18 and from unpaid carers of disabled people who also had parental responsibility for a non- disabled child. More than half (54%) of the former and four in ten (40%) of the latter also have caring responsibilities for more than one additional person. The largest proportion of both groups, 77% and 62% respectively were caring for 50 hours or more each week.

There is clear and long-standing evidence that caring and disability impacts on incomes. A third of both groups were struggling to make ends and a quarter were struggling to afford the costs of food. Four in ten were cutting back on essentials and building unsustainable debt on credit cards and overdrafts to make ends meet.

Source: State of Caring 2023, Carers Scotland Impact of caring on finances	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
Struggling to make ends meet	33%	33%
Struggling to afford cost of food	26%	25%
Struggling to afford utility bills	17%	18%
Struggling to afford housing costs	6%	7%
Struggling to afford the cost of care	11%	9%
Cutting back on essentials	39%	40%
Using foodbanks or food pantries	17%	12%
Using credit cards to make ends meet	43%	44%
Using overdrafts to make ends meet	38%	39%
Spending on incontinence products	25%	17%

These families face also additional costs over and above households without care for a disabled person, including care, products and transport. Around one in ten of both groups said that they were struggling to afford the cost of care and many were spending their limited incomes on other care and disability costs such as incontinence products.

“I pay for a lot of additional things such as continence products, which I cannot afford This is having a detrimental effect on my life as a single parent of two growing boys.” (Carer, State of Caring 2023)

“Our daughter has needed a lot of support and weekly CAMHS appointments, petrol has been expensive to travel to the city.” (Carer, State of Caring 2023)

These financial challenges unpaid carers face are exacerbated by a lack of appropriate and accessible services, including education. Half of parent carers and a similar proportion (47%) of those unpaid carers of disabled people who also had parental responsibility for a non-disabled child said that support services do not meet their needs or those of the person they care for. Less than half of both groups (47%) had been able to have a break from caring in the last 12 months. Only around a third (30%) of the former and a quarter of the latter said that they felt they could rely on social services.

“Complete lack of support for son. Huge difficulty being awarded adequate support for mother.” (Carer, State of Caring 2023)

“Additional support out with normal school hours has been withdrawn significantly impacting our mental health, my daughter mental health and development potential and also impacting our ability to remain in employment.” (Carer, State of Caring 2023)

“Care is inconsistent - we seem to go for cheap, rather than properly signed off and trained carers. A new agency is being pushed on us that don't have experience in children with disabilities. Respite is non-existent - it lets us go to work, but we worry what we're coming home to.” (Carer, State of Caring 2023)

This lack of support and rigid benefit rules often means that, for too many, paid employment is difficult. The table below sets out the impact of caring on employment for both groups.

Source: State of Caring 2023, Carers Scotland Impact of caring on employment	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
Have given up work to care	38%	34%
Have reduced their working hours	39%	31%
Have taken a less qualified job or turned down a promotion	19%	21%

When asked why they had had to take these actions to be able to manage their caring role, a third (33%/34%) of both groups cited not being able to find suitable replacement care services and a similar proportion (31%/25%) a lack of support from the NHS and social services. Affordability of replacement care services was also an important consideration for around 1 in 5 (21%/18%) of these unpaid carers.

“[My] child needed to be home educated due to high anxiety and no availability of suitable education places.” (Carer, State of Caring 2023)

“Not possible to work. No specialist provision or education that was available that was suitable.” (Carer, State of Caring 2023)

However, within both groups, unpaid carers are continuing to juggle work and care, often at the expense of their own health and wellbeing. Just over half (22% full-time 31% part-time) of parent carers and a similar proportion (30% full-time, 27% part-time) of unpaid carers of disabled people who also had parental responsibility for a non-disabled child were able to be in paid employment. But, the challenges of managing

paid work and care often leaves unpaid carers exhausted and isolated.

“I am constantly juggling work and my carers role. My employer is flexible with my hours but I always need to make the time back which is challenging. I reduced my working hours to help me cope better but it has been a struggle financially and emotionally as I am isolated.” (Carer, State of Caring 2023)

“I’m a single mum - I feel like I’m robbing my son of time when my employer says I have to make up hours as I end up working until bedtime, which leaves him unregulated, which makes things worse the next day. I feel like I’m robbing my team if I can’t deliver within (sometimes

unreasonable) timescales and have ended up working to 1:40am before while my son slept

because they dropped last minute deadlines on me. I don’t get to switch off - and now my team is reducing a large proportion of roles at my grade, so it’s only going to get worse.” (Carer, State of Caring 2023)

And for those able to juggle work and care, choice of work and subsequent earnings are impacted by what support, including carer benefits, are available. The following table sets out some of the implications on monthly earnings for unpaid carers.

Source: State of Caring 2023, Carers Scotland Average monthly loss of earnings	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
£2000 or more per month	12%	14%
£1000-£1900 per month	28%	33%
£500-£999 per month	30%	32%

“I earn too much for Carers Allowance, but am limited by my caring role to earn more, I work 18 hours a week term time only, leaving me with a low income and no way to improve it.” (Carer, State of Caring 2023)

“I have had to give up my permanent hours, and am now on relief contract of zero hours. It gives me flexibility to care for my son, but if I cannot work when I am scheduled, then I do not get paid.” (Carer, State of Caring 2023)

“My employer has been really understanding but I am on a casual contact, which means I miss out on a lot of benefits of regular employment although I have flexibility. Often if my daughter is struggling then I struggle, and this is difficult because I have a role which requires me to speak to people who are also struggling.” (Carer, State of Caring 2023)

“I am working day and night 4 part time jobs which fit around the care for my son. He is getting far less attention from me. I need to pay the bills and stay out of debt. I never get a day off I have no sick pay so can’t be ill. Worry worry worry. Work work work.” (Carer, State of Caring 2023)

This lack of support from public services and a co-ordinated approach means that too many unpaid carers, and subsequently, children within their families, are left facing

poverty and ill health.

Organisations that support unpaid carers with other protected characteristics such as being from minoritised ethnic communities often find intersectional issues at play which can lead to worse financial outcomes for families. For instance, at the 2011 census 11.7% of members of the Gypsy/Traveller community were unpaid carers, although with members of the Gypsy/Traveller community being more likely to suffer from long-term health conditions than the general population, this is likely to be an underestimate and there is evidence of a lack of self-identification as an unpaid carer due to cultural norms. This contributes to worse economic outcomes for families from the community¹¹.

Young Carers

Scottish Government recognise that there around 800,000 unpaid carers in Scotland, including an estimated 30,000 young carers. The Scottish Government's *Young Carer: review of research and data report 2017*ⁱ shows that, "Higher rates of caring by young people are found in areas of greater deprivation and amongst groups with lower incomes. The Census data shows that young people in the most deprived areas provide more care than in wealthier areas."

In 2023, there were 6,548 young carers recorded on SEEMiS. However, there is no comparable data showing the number of young carers in receipt of wider benefits, such as free school meals. More data is needed so that young carers in poverty have access to the much-needed support that they need and are entitled to.

Carers Trust's annual Young Carer Survey 2023 "Being a young carer is not a choice. It's just what we do"ⁱⁱ found that 66% of respondents said the cost-of-living crisis is affecting them and their family. A further 36% said they face additional costs because they are a young or young adult carer.

"Not being able to afford the basic things such as shower gel or toilet roll and not being able to afford heating." (Young carer)

"I worry about making sure my dad has everything he needs for his diabetes and to keep him warm through winter and make sure he's fed properly. The cost of food, heating and electricity is going through the roof." (Young Carer)

2. What difference has the statutory framework made to the way local authorities and health boards have approached reducing child poverty?

Publications of local Child Poverty Action Plans mean that there is more accountability and transparency. It has shown that partnership working with local authorities, health boards and other partners can make reducing child poverty a top priority.

3. What difference has having the targets, delivery plans and reporting requirements built into the Act made at a national level?

This has provided greater visibility and has supported focus in investment and actions

¹ MECOPP:

<https://static1.squarespace.com/static/62f4f5fa696d570e19a69429/t/639759b3821fc401f13d40c7/1670863284452/Briefing+sheet+15.pdf>

to reduce child poverty.

4. The Act set up several scrutiny measures. How effective have these been?

Despite this visibility, it is unclear whether there is sufficient intersectional analysis of future actions and areas for investment. An example, as outline above, the crucial role of social care and accessible education and childcare for families with a disabled child or adult.

5. If you were involved in scrutiny of the Bill in 2016/17, has it had the impact you expected?

N/A

6. What does the implementation of the Act tell us about the effectiveness or otherwise of statutory targets as a way of driving policy?

N/A

7. Do you have any other comments?

Although not part of the framework of the Child Poverty (Scotland) Act 2017, there have been other initiatives by Scottish Government for young carers implemented. The Young Carer Grant was introduced in 2019 and is a grant of over £380 that young carers can apply for. To be eligible for Young Carer Grant, young carers must be aged between 16 and 18 years old, be caring for 16 hours a week or more, and be caring for someone on a qualifying disability benefit. Unfortunately, if there is more than one young carer aged 16 to 18 years in the household then only one can apply for the grant. The

National Carer Organisations recommend that the regulations change to allow for multiple young people being eligible for the grant for providing care for the same cared-for person.

Any young person in Scotland who provides care to someone, and is aged 11-18 inclusive, can sign up for the Young Carers Package, delivered through Young Scot. This a package of non-cash benefits, such as subscriptions and wellbeing boxes. The Young Carers Package also includes a package of support for 18 year olds who are transitioning out of eligibility for the Young Carers Package. 18 year olds that had signed up to the Young Carers Package can claim a £100 voucher to help with whatever the next phase of their life holds.

Recent amendments to Carer Support Payment allow unpaid carers aged 16-19 in full-time 'non advanced' education to apply for this benefit if they have certain exceptional circumstances - including if they have no support from parents or are responsible for a child or young person. However, the National Carer Organisations are calling for Scottish Government to extend entitled to all unpaid carers over 16 years old in full-time non-advanced education to ensure equity, reduce unnecessary complexity and to ensure unpaid carers feel valued, tackle poverty experienced and get the financial support they need and deserve. In addition to the above changes, the National Carer Organisations strongly recommend that Job Start Payment to include Carer Support Payment as a qualifying benefit to help young carers and young adult carers with the additional costs associated with the transition into paid employment.

Incorporation of UNCRC in Scotland means that children and young people, including young carers have more power to act when their rights have not been respected. It means that there is greater accountability when their rights are breached. Several of the articles play a key part in reducing child poverty in Scotland and should be included in framework. Scottish Government have made it clear that tackling child poverty is their number one priority. For Incorporation of UNCRC and reducing child poverty in Scotland to be successful, Scottish Government needs to provide long-term adequate funding. Scottish Government need to listen to frontline staff working with families and children in Scotland to able to implement change at the core.

Recent research by Carers UK and WPI Economics² further evidences the scale of poverty amongst unpaid carers and their families. The report found that 1.2 million unpaid carers across the UK live in Poverty (including an estimated 100,000 in Scotland), and 400,000 live in deep poverty in the UK. The poverty rate experienced by unpaid carers and their families was 50% higher than those who did not provide care. And one in ten unpaid carers live in deep poverty. The research found that an inability to participate in paid work, caring for long hours, increased cost of living, lack of support and access to formal care services, and receiving income-related benefits are the strongest predictors of poverty amongst unpaid carers and their families. The National Carer Organisations welcome Scottish

Government's approach to extend entitlement and develop social security support for unpaid carers. However, more needs to be done apace to tackle poverty impacting unpaid carers and their families.

Scottish Government should carry out a review of the current support provided to unpaid carers through the social security system and implement interventions to tackle poverty experienced by unpaid carers and their families as soon as practical.

Submitted by Paul Traynor, Kelly Munro and Fiona Collie on behalf of the National Carer Organisations.

² https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Appendix

Carers Scotland: State of Caring 2023 Data on unpaid carers with children

Carers Scotland's annual State of Caring survey has been undertaken for over a decade and is Scotland's most comprehensive research into the lives and experiences of unpaid carers. The 2023 survey was carried out

between June and August 2023 and completed by 1,771 unpaid carers in Scotland.

The information in this document represents the responses from 294 parent carers with a child under 18 and an additional 234 unpaid carers who as well as providing care for a disabled family member also have parental responsibility for a child(ren) under 18.

About

Age	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
25-34	4%	8%
35-44	37%	29%
45-54	43%	41%
55-64	13%	15%
65 and over	3%	7%

Hours of care provided	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
34 and under	7%	22%
35-49	16%	16%
50-69	12%	8%
70-89	8%	5%
90 hours or more	57%	49%

More than half (**54%**) of parent carers and **40%** of unpaid carers who also have parental responsibility for a non-disabled child under 18 also provide care for two or more people.

Four in 10 (**40%**) of parent carers and **28%** of unpaid carers who also have parental responsibility for a non-disabled child under 18 also have a disability, as described under the Equality Act.

Financial

	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
Struggling to make ends meet	33%	33%
Struggling to afford cost of food	26%	25%
Struggling to afford the cost of care	11%	9%
Struggling to afford utility bills	17%	18%
Struggling with housing costs	6%	7%
Are in debt	20%	20%

Carers talked about a range of ways they were trying to manage the financial struggles they are experiencing and make ends meet.

	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
Cutting back on essentials eg. food and heating	39%	40%
Using credit cards to make ends meet	43%	44%
Using bank overdraft to make ends meet	38%	39%
Borrowing from friends and family	21%	25%
Using buy now pay later services	37%	30%
Fallen into arrears with utility bills	13%	11%
Falling into arrears with rent or mortgage	5%	6%
Using foodbanks	9%	8%
Using food pantries	6%	6%

This level of financial struggle meant that carers were worried about the cost of living, with 78% of parent carers and 73% of unpaid carers with parental responsibility for a non-disabled child said that this had impacted on their health. Similar proportions – 78% and 68% respectively are finding it more difficult to manage financially and 80% of both groups worried about their ability to save and plan for the future.

Quotes from unpaid carers:

Costs of food and energy

“My sons only eat specific snacks and foods our shopping bill has tripled and I am

worried it will continue to rise and we will need to cut out these snacks, which will have detrimental effect on them”

“Constantly watching the smart meter. Not using the tumble dryer and then worrying when it rains because I can't get clothes dry. I have stopped using my oven and I used to love to bake.

Don't ask family for dinner anymore because of the cost of buying the food and cooking it plus having the heating on. My house is cold because the heating isn't on as much.”

“We were cold over most of the winter being forced not to use gas central heating for more than a couple of hours a day and relied instead on hot water bottles. It was very uncomfortable for us. We took showers at the local pool to save using hot water.”

“Living on Universal Credit is extremely difficult, particularly as I previously earned upwards of £45k. I am good at managing money but I have been forced to use foodbanks and to cut back on essentials like toiletries and cleaning products in order to survive.”

“What little family time we had is now unaffordable. Everything is now cost living only.” “I can afford because I go without and tightly manage a budget.”

Impact on ability to take part in activities, sport and leisure

“There are activities I take my disabled children to where I could pay to join in but I can't afford it. I've leisure and sports. Carers often don't count for discounted prices.”

Housing

“I have been unable to do adaptations to house and have no flooring following a flood as can't afford to replace”

“I'm not in arrears with my mortgage yet but my current job ends in two months and I can't see where else I can work when two family members in different locations need almost 24/7

support (note I regularly need to take my daughter with autism to work with me)”

Limits to paid work because of caring

“I am working day and night 4 part time jobs which fit around the care for my son. He is getting far less attention from me. I need to pay the bills and stay out of debt. I never get a day off I have no sick pay so can't be ill. Worry worry worry. Work work work.”

“Being a one wage family and inflation not meeting wages or benefits incomings is having a big impact that will affect us in the future if something doesn't change. Carer's Allowance is not enough for the work I undertake”

Additional costs of care:

Unpaid carers in both groups had additional costs because they are caring. One in 10 unpaid carers with parental responsibility for non-disabled child and 14% of parent carers are paying for specialist childcare for their disabled child, with 17% and 25% respectively paying for

incontinence products. A third of both groups have other childcare costs.

“Our daughter has needed a lot of support and weekly CAMHS appointments, petrol has been expensive to travel to the city.”

“I pay for a lot of additional things such as continence products, which I cannot afford This is having a detrimental effect on my life as a single parent of two growing boys.”

Social Security:

Unpaid carers in State of Caring 2023 were asked which social security or other benefits they received, if any.

Carer Benefits	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
Carer’s Allowance & Carer’s Allowance Supplement	52%	44%
Income Support with Carer Premium	5%	6%
Universal Credit with Carer Element	22%	18%

Other benefits and financial support	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
Scottish Child Payment	48%	34%
Child Tax Credit	32%	23%
Income Support without Carer Premium	4%	3%
Universal Credit without Carer Element	6%	6%
Jobseekers Allowance	1%	2%
Employment Support Allowance	5%	3%
Incapacity Benefit	1%	2%
Working Tax Credit	10%	9%
In receipt of Council Tax Reduction	24%	17%
In receipt of a Discretionary Housing Payment	2%	0%

For those parents with a disabled child under 18, 49% received Child Disability Payment.

However, half of both groups (50%) of parent carers and 50% of those unpaid carers with parental responsibility for a non-disabled child under 18 said that they needed more financial support, with 48% and 42% respectively saying specifically that they needed more social security support.

Worrying, more than four in 10 (45% and 40% respectively) knew what benefits they were entitled to as a carer.

Employment

Many unpaid carers in State of Caring 2023 reported that they were paid work alongside their caring responsibilities.

Status	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
Working full-time	22%	30%
Working part-time	31%	27%
Self-employed full-time	0%	1%
Self-employed part-time	6%	2%
Not in paid work	29%	24%
Other	12%	16%

For those in employment, more than half juggled care with 30 hours or more of paid employment.

Hours of work	Parents with a disabled child under 18	Unpaid carers who also have a non disabled child under 18
30 hours or more	52%	56%
20-29 hours	25%	26%
10-19 hours	20%	14%
Less than 10 hours	3%	4%

However, a significant proportion had given up work, reduced their hours or taken on a less qualified job/turned down proportion because of the challenges of juggling work and care.

Impact of caring on employment	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
Have given up work to care	38%	34%
Have reduced their working hours	39%	31%
Have taken a less qualified job or turned down a promotion	19%	21%

When asked why they had given up work or reduced hours, unpaid carers provided cited stress and impact on their health and wellbeing, lack of replacement care and lack of support from their employer.

Impact of caring on employment	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
Stress of juggling work and care	71%	70%
Changed needs of the cared for person	61%	58%
Feeling too tired to juggle work and care	60%	56%
Not being able to find suitable replacement care	33%	34%
Lack of support from the NHS/social services	31%	25%
Not being able to afford replacement care services	21%	18%
Lack of support from employer	17%	13%

And for those able to juggle work and care, choice of work and subsequent earnings are impacted by what support, including carer benefits, are available. The following table sets out some of the implications on monthly earnings for unpaid carers.

Average monthly loss of earnings	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
£2000 or more per month	12%	14%
£1000-£1900 per month	28%	33%
£500-£999 per month	30%	32%

Quotes from unpaid carers:

“I earn too much for carers allowance, but am limited by my caring role to earn more, I work 18 hours a week term time only, leaving me with a low income and no way to improve it.”

“I have had to give up my permanent hours, and am now on relief contract of zero hours. It gives me flexibility to care for my son, but if I cannot work when I am scheduled, then I do not get paid.”

“I am constantly juggling work and my carers role. My employer is flexible with my hours but I always need to make the time back which is challenging. I reduced my working hours to help me cope better but it has been a struggle financially and emotionally as I am isolated.”

“Find it hard to juggle start time for work. As well as caring I have a 5 year old child I have to take to school each day as his Dad who I care for can't. Also difficult to find out of school care to enable me to work and do caring responsibilities. Flexible work start times or ability to reduce working hours to make caring easier for a period of time.”

“My employer has been really understanding but I am on a casual contract, which means I miss out on a lot of benefits of regular employment although I have flexibility. Often if my daughter is struggling then I struggle, and this is difficult because I have a role which requires me to speak to people who are also struggling.”

“There’s very little interest in helping carers to stay in work and using budgets to enable this. Losing our work (and mortgage) would be catastrophic for public services - better for all to keep us working but social services don’t really see this as their role to support.”

“Highland Council used to provide daughter's taxi from school to after school club 1 day/week, but no longer do this so I have to cut my work day short (I only work 7 hours!) in order to do this myself now.”

“I’m a single mum - I feel like I’m robbing my son of time when my employer says I have to make up hours as I end up working until bedtime, which leaves him unregulated, which makes things worse the next day. I feel like I’m robbing my team if I can’t deliver within (sometimes unreasonable) timescales and have ended up working to 1:40am before while my son slept because they dropped last minute deadlines on me. I don’t get to switch off - and now my team is reducing a large proportion of roles at my grade, so it’s only going to get worse. My employer is responsible for setting guidance for others, including around autism, but it doesn’t feel like we actually believe it when I see how I’m treated as a carer for an autistic kid with autism myself.”

“If I could afford to I would give up work to focus on my son but I can’t keep the wolf from the door without some earned income. My mum is my son's registered Carer and she receives underlying Carers' Allowance but this does not qualify her for the additional Carer payments in Scotland. It seems unfair that she is providing full time hours worth of caring but is not financially compensated in the same way as other carers are. I could not manage my son without her, she is helping save the state hundreds of thousands of pounds.”

“Child needed to be home educated due to high anxiety and no availability of suitable education places.”

“My daughter no longer was able to attend school. I am a single parent”

“School and social work no help. My daughter was suicidal and I couldn’t leave her home alone.”

“Attendance in school has been very sporadic. We have changed schools and are flexi schooling now... This is much better but still only gives me a small window of time”

“Made redundant and I can’t find part-time flexible work”

“Not possible to work no specialist provision or education available that was suitable”

Carers were asked what might help them be better able to juggle paid employment with care.

What would help juggle work and care	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
A change of eligibility criteria for Carer Support Payment	96%	91%
More reliable health and social care services	95%	90%
More affordable and accessible care	94%	92%
A carer passport at work	93%	92%
Paid carers leave	67%	71%
Employer recognition	52%	49%
Understanding line manager	30%	29%
Working from home sometimes	25%	33%
Working from home all of the time	21%	25%
Flexible working	19%	24%

Note: significant proportions stated that they already had a supportive line manager and/or were able to access flexible working.

Other areas that would assist - quotes from unpaid carers:

“More wrap around care for disabled children.” And “Normal school hours is not long enough days for childcare for my area of work. There is a definite gap for specialist/ increased support in wraparound care for before/after school club for children with ASN”

“For the NHS to have a more organised team to care for my child. So I don’t have to attend as many appointments. Surely, they can all update the system and have one person who I would work with who could explain the medical information to me so I don’t have to see the audiologist/feeding team/developmental team/optometrist etc...”

Practical support and health and wellbeing Services:

Many in State of Caring 2023 said that they did not have the support needed in their caring role and set out what they need

Experience of services and support	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
Services do not meet the needs of me or the person I care for	50%	43%
Services do not enable me to have a break from caring	47%	47%
I have not had a break from caring in last year	44%	34%
I can rely on social services	30%	25%

Experience of services and support	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
I need increased choice of support services	52%	49%
I need more breaks or time off from my caring role	56%	50%

Quotes from unpaid carers:

“Complete lack of support for son. Huge difficulty being awarded adequate support for mother”

“Provision is good, just not enough provided and have to fight for it, not easy to access.”

“Social work does provide funding but they do not help at all with finding people to employ and that is a huge challenge.”

“Additional support out with normal school hours has been withdrawn significantly impacting our mental health, my daughter mental health and development potential and also impacting our ability to remain in employment.”

“I understand the immense pressure that everyone is under but i am constantly disregarded when i voice my concerns and nothing is done to try and alleviate the problems.”

“Care is inconsistent - we seem to go for cheap, rather than properly signed off and trained carers. A new agency is being pushed on us that don't have experience in children with disabilities. Respite is non-existent - it lets us go to work, but we worry what we're coming home to.”

“Day centre our daughter attends is fantastic. Still have 18 hours of care package not picked up (to help once daughter is home from her day centre to allow us to work)”

“I feel social care are not listening to what I'm saying.”

Health and wellbeing:

Most of those responding to State of Caring 2023 reported that caring was having a negative impact on their physical and mental health.

Health and wellbeing	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
I feel stressed and anxious	88%	82%
I feel lonely	62%	50%
My physical health has suffered from caring	61%	55%
I feel depressed	58%	58%

I have put off my own health treatment because of my caring responsibilities	55%	47%
My mental health is bad or very bad	41%	31%

Quotes from unpaid carers:

“Trying to hold down a job and have a full-time caring commitment is draining both physically and mentally.”

“My relationship with my other children, partner and friends is negatively impacted due to the time taken up caring for my daughter. I am constantly playing catch-up with housework, etc, and house repairs rarely get done either”

“Particularly when my son was at a different school who were unable / not willing to meet his needs, I became very depressed and anxious and found day to day life very difficult to cope with. When my son didn't want to live anymore, I took this on board as being my fault and this had huge implications as to how I felt I was failing him”

“Has impacts on all activities we can do as a family that others take for granted e.g. visiting and staying with family, going on holiday, time away just as a couple”

“Single parent caring for 2 young people while I have complex ptsd, depression, anxiety and spinal issues so am in pain regularly.”

“It is exhausting and time consuming on top of a full-time job. I sometimes feel I don't exist.”

“The first things that are reduced when you have a caring role are the things that bring joy, happiness and health to the carer. Those things that improve your own life. Exercise, healthy eating and socialising. These seem unimportant when compared against another person's immediate personal needs. Over tie this takes a huge toll on physical and mental wellbeing.”

“I don't have time to do things I had planned. I don't like going away anywhere as I worry and have to do so much in advance of going away it's hardly worth the stress and effort. My life is no longer my own, my life is caring for others. I don't mind, it's my Dad and my mother in law and my children. But I never expected my life to be one of caring all of the time and so many self- sacrifices to do so.”

“I have been aging much quicker since my caring role expanded. I don't expect to live as long as I as expecting because of it.”

Individuals were also sked what could help their physical and mental health. The following represents the most popular responses.

What would help unpaid carers' health	Parents with a disabled child under 18	Unpaid carers who also have a non-disabled child under 18
More support for my own health and wellbeing	68%	67%
A break from caring	66%	62%
Having good quality services for the person I care for	42%	49%
Being in paid employment	40%	41%
Being able to take part in training or education activities	25%	23%

ⁱ <https://www.gov.scot/publications/young-carers-review-research-data/pages/3/>

ⁱⁱ <https://carers.org/downloads/being-a-young-carer-is-not-a-choice--its-just-what-we-do---final-scotland- summary.pdf>