

Pathways to Work: Reforming Benefits and Support to Get Britain Working Consultation Response

Unpaid carers

An unpaid carer is someone who is providing care and support to a family member, partner, friend, or neighbour who is disabled, has an illness or long-term condition, or who needs extra help as they get older. This support can include, for example, assisting with daily tasks like bathing, dressing and eating, managing medication and providing emotional support. There are 627,715 unpaid carers in Scotland, including 13,652 of whom aged under 16¹.

Introduction

This response is provided by the National Carers Organisations (NCOs) in Scotland to the UK Government [“Pathways to Work: Reforming Benefits and Support to Get Britain Working”](#) Green Paper.

Our response does not intend to respond in depth to the consultation, but instead to set out our concerns over the detrimental impact such reforms would have on unpaid carers. Quite simply, we believe that the UK Government should pause the reforms *completely* and think again.

The NCOs have consulted with unpaid carers through a range of surveys and polling. We have included a selection of data and quotes from unpaid carers throughout the response.

Some proposals in the Green Paper are welcome, such as additional support for disabled people to access employment and an increase in the standard rate of UC (Universal Credit). High-quality and accessible employment support for disabled people and unpaid carers is important, but it must recognise the challenges of disability, ill health and caring and be delivered in a way that does not include work-related conditionality and sanctions. The UK Government must also work closely with devolved employability services, including the Scottish Government, to ensure that the best support is available to individuals, tailored to their needs. The UK Government must also develop clear plans to use its powers to reduce the barriers in society for disabled people and unpaid carers that often prevent or reduce access to employment and utilise their legislative and procurement powers to influence employers, including public bodies, to create the real change that can support the delivery of fair work that is accessible and sustainable.

However, whilst we do welcome these provisions, and the recent announcement that existing claimants will be protected from reductions in their entitlements, **the National Carer Organisations believe that much of what is proposed will be devastating for disabled people and unpaid carers for years to come.** Every day, nearly 1000 people in Scotland become unpaid carers. This can happen suddenly or as a condition deteriorates or progresses. However, whether a longstanding or a short-term situation, disabled people and unpaid carers should be able to expect that social security support is there to provide the safety net they need.

The financial impact of tightening eligibility criteria for essential disability and carer benefits, including within UC, could severely impact unpaid carers and disabled people, increasing poverty amongst households who will face some of the highest levels of financial insecurity.

As organisations representing unpaid carers, we are particularly concerned about the significant impact the reforms will have on unpaid carers – now and in the future. Changes will increase the detrimental impact of caring on unpaid carers - poverty, financial insecurity, loss of career and poorer health. The DWP’s own [impact assessment](#) estimated that 150,000 unpaid carers in the UK would have lost access to

Carer's Allowance and Carer Element in UC by 2029/30 as a result of the tightening of eligibility criteria in PIP (Personal Independence Payment).

Even with revised proposals, at least 150,000 people will be pushed into poverty, with many unpaid carers in the coming years finding themselves unsupported, with no independent income that recognises the impact of their caring role and experiencing significant detriment simply because they began caring at a later date.

Furthermore, the proposals also do not recognise that there is potential for a doubling of the impact of these reforms on disabled unpaid carers. Many unpaid carers in the future who have or develop health conditions or disabilities themselves, could be barred from access to both reserved Health and Carer Elements– a twofold impact. A third (33%) of unpaid carers in Scotland are disabled (compared to 24% of non-carers) and research during Carers Week found that 41% of current and former carers in Scotland had either a mental or physical health condition develop or become worse when they were providing careⁱⁱ.

“I think this will be disastrous for myself and others in similar situations. The extra costs we face as carers will not disappear if the Health Element is cut. And for those of us like myself who are carers AND disabled, this will be a double whammy. Life as a carer is already stressful without having to worry about the cruelty of cuts to our benefits.”

(Unpaid carer during consultation with NCOs)

The proposals will also have a disproportionate effect on women. Unpaid caring is highly gendered. Women make up 58% of all unpaid carers and are 38% more likely to be providing intense careⁱⁱⁱ. More than two-thirds (69%) of those in receipt of Carer's Allowance are female^{iv}. Reform of social security has wider implications for the financial independence and long-term economic wellbeing of female unpaid carers.

“Losing any of these benefits puts significant strain on those families who provide support to disabled adults especially if those adults still live in the family home. I am not able to work due to my caring responsibilities and thus have no financial independence and have to rely on my husband's income. This is a severe threat to women's financial independence even with Carer's Allowance and could cause significant distress if the marriage was to breakdown.”

(Unpaid carer during consultation with NCOs)

“I am so fearful for the future, I'm no longer young and afraid what will happen to my son when I'm gone”
(Unpaid carer during consultation with NCOs)

Recommendations

The UK Government should pause the proposals and consult and engage with disabled people, unpaid carers, and their representative organisations and develop full and comprehensive impact assessments, including of shifting of costs including to public services such as health and care.

The consultation has not involved the very people it will affect. The voice of lived experience has been missing from the outset. The green paper contains 22 policy changes, yet only 11 of these are being consulted on. These include significant changes to the PIP daily living component; freezing, reducing and restricting the UC Health Element; scrapping the Work Capability Assessment; and the development of a new “Health Element” based on revised PIP assessments.

The changes and the numbers of disabled people, unpaid carers and their families affected by these changes are so significant that it seems incomprehensible that the UK Government has not consulted from the outset on these proposals with the people most affected. It is difficult not to conclude that this has been to silence critical voices.

“The stress of yet another 'hostile environment' but this time directed at disabled people is overwhelming.”

(Unpaid carer during consultation with NCOs)

The National Carer Organisations believe that **the proposed restrictions on PIP and changes to means-tested benefits should not be implemented, and any changes to improve the benefits should be developed in consultation with disabled people and unpaid carers. Whilst the Government has now indicated that existing claimants will be protected, which is welcome, it is simply unacceptable that individuals who become sick or disabled thereafter and their unpaid carers will not be fully supported.**

We also believe that, should the UK Government decide they wish to continue with these reforms of social security, **they should commit to pausing the process of legislation, making no changes to social security payments until full engagement and statutory consultation is undertaken with disabled people and their unpaid carers on all proposals.**

This should include a comprehensive Equality and Poverty Impact Assessment for both disabled people and unpaid carers, the results of which should be fully taken into account in revised proposals. The majority (98%) of unpaid carers in the NCOs surveys believe that the UK Government had not considered the implications for unpaid carers of the reforms of disability benefits. This is simply not acceptable.

There has been an unfortunate impression given that PIP is an out-of-work benefit rather than one to support the additional costs of the disability (including support that enables disabled people to be in paid employment). The current social care system does not currently meet the needs of disabled people and their unpaid carers, nor the additional costs to replace the care provided by unpaid carers and/or the costs of care supported by disability benefits.

In Carers Scotland's research, just 20% of unpaid carers had received an assessment of their needs (an Adult Carer Support Plan) in the last 12 months. Of these, 39% had received no support and 64% had areas of support identified but these supports were not provided¹. In the NCOs consultation on this Green Paper, many unpaid carers told us they had already seen reductions in social care, with 27% saying these cuts had a severe impact upon them, and 65% a significant one. Almost all (97%) said that the reform proposals would make it harder for them to provide care.

Therefore, **a full assessment must be undertaken to consider all costs**, including to other public services such as health and social care and estimate the impact on employment that the loss of such benefits will have on disabled people and unpaid carers. It is the NCO's view that these reforms simply move costs onto families and public services, and risk the current and future employment prospects of disabled people and unpaid carers. **Removing social security entitlements does not change health conditions nor does it reduce the need for care** – changes simply increase the challenges that unpaid carers face in providing care, risking the invaluable support they provide.

“[if the changes go ahead] I would have to work the equivalent of 2 jobs to make ends meet, or my husband would need support outside our household with carers coming in while I work, [which] cost more than £89 per week¹.”

(Unpaid carer during consultation with NCOs)

“How can the government first take away our paid carer and social care, leaving only me to look after the disabled family I have, then expect me to work because we have no finances.”

(Unpaid carer during consultation with NCOs)

¹ The approximate value of Carer's Allowance.

The UK Government should also, in their financial planning for any subsequent legislation to support the proposals or change social security, **provide additional funding for third sector and local authority advice services to support disabled people and unpaid carers** understand the changes, navigate the new systems and claim all benefits to which they are entitled. This should include **additional funding for advice to be distributed via the devolved administrations** to support individuals in each of the nations to navigate the complexity of devolved and reserved system changes. The NCOs consultation around the reforms found that a significant proportion (62%) of unpaid carers are unsure how the UK Government's proposals would affect them and would require advice. Resources are needed to provide such additional advice.

“Like everyone else in this position I’m scared. Getting any benefits is hard and an unpleasant experience and having to go through the process time and again is wearisome.”
(Unpaid carer during consultation with NCOs)

The UK Government should pause the proposals to change the Health Element and should consult and fully engage with the Scottish Government to minimise any negative impacts of interactions between reserved and devolved social security systems for disabled people and unpaid carers.

The NCOs believe it is deeply unfair that new claimants for the UC Health Element will receive less financial support than existing claimants. This will affect the household income of disabled people, unpaid carers and their families who apply for the benefit after the cut-off date, where the unpaid carer is living with the person they care for. The reduction of the Health Element to £50 a week for new claimants will have a very severe impact on families.

Over a third (38%) of unpaid carers in our consultations said that they or someone in their household would be affected by proposals to reduce the Health Element of UC. Two thirds (65%) said that this would have a big impact on their household. The majority (89%) said that this proposal was unfair. Whilst new Government proposals will provide protection for existing claimants, this reflects the views of unpaid carers of the fundamental unfairness of reducing support for people who are sick or disabled.

“Although this will not affect my household, in my view this makes no sense. There are many people who receive PIP which helps them to continue working in some capacity. But there are also many people who are simply unable to work and rely on the additional UC Health Element to help mitigate the additional costs associated with their conditions.”
(Unpaid carer during consultation with NCOs)

“This will have a huge impact as my daughter continues to deteriorate, so costs continue to rise, yet they are freezing the disability part! What planet are these folk on?!”
(Unpaid carer during consultation with NCOs)

“Shocking what they are doing. My husband can’t work... he has tried but keeps getting paid off due to sickness and inability to work.”
(Unpaid carer during consultation with NCOs)

The NCOs are also concerned about the effect on young disabled people and their unpaid carers. The consultation also includes proposals to delay access to the Health Element of UC until someone is aged 22, by switching resources into an expanded Youth Guarantee, and on raising the age at which people can claim PIP. In line with our general concerns around the effect of changes on the Scottish Block Grant, it is vital that access to Adult Disability Payment is not constrained for young disabled people. For young people with a disability or long-term health condition and their unpaid carers, transition can be a time where they see a sharp drop in the support they receive from health and social care services^{vi}. Financial support that recognises the additional costs of disability and that supports independent living, including access to employment, is vital to supporting their steps into adulthood.

Over a quarter (27%) of unpaid carers in our consultations said that they or the person they care for would be affected by delays to accessing the UC Health Element until the cared-for person is 22. More than half (61%) said that this change would negatively affect them.

“I don't agree with this. People don't suddenly become disabled after a certain age. Anyone can become disabled at any time and it's unfair to not support those who are deemed too young to qualify for help.”

(Unpaid carer during consultation with NCOs)

“My sons both receive LCWRA so will not be affected but they benefited in so many ways from having this money. As disabled young people they are on a slower trajectory to work, college and independence than the average young person and being able to have experiences in the community with support from mum or dad or a service is essential for their growth and personal development. It costs them more to achieve the same as their peers and taking away this financial support will lead to more inequality.”

(Unpaid carer during consultation with NCOs)

There continues to be no clarity on whether Adult Disability Payment in its current form will fully remain as a passport to the Health Element in future and continue to support unpaid carers' access to the Carer Element in means-tested benefits such as UC. Loss of support could mean even more unpaid carers will struggle to afford essentials like food and heating. In research by Carers Trust Scotland^{vii}, 74% of unpaid carer respondents were worried about being able to afford energy bills, and 12% have used a food bank (Carers Trust Scotland, 2022). Many unpaid carers who could be affected will face significant financial hardship because of their caring role. Our research shows that an estimated 100,000 unpaid carers in Scotland are living in poverty, with levels of poverty 56% higher and deep poverty 60% higher than those without caring responsibilities^{viii}.

There may also be interactions which could restrict eligibility for certain devolved benefits, such as Scottish Child Payment, which is passported through UC. These interactions appear not to have been considered at all within the reform plans.

Changes that impact unpaid carers and disabled people in Scotland will create additional complexity for both individuals and the system. Furthermore, such additional complexity in claiming reserved benefits will also increase demand for advice and support from third sector and local authority advice services, including local carer organisations. As a consequence of the cost-of-living crisis, reducing budgets, and increasing costs (such as employer NIC), local carer organisations are already experiencing significant and increased demand with at best standalone resources. It is worth repeating that a significant proportion (62%) of unpaid carers were unsure how the UK Government's proposals would affect them and would require advice.

The NCOs believe that the **proposed restrictions on the Health Element, including limiting to those over 22 should not go ahead**, and any changes to improve the benefits should be developed with disabled people and unpaid carers.

The NCOs believe that, should the UK Government continue to pursue these changes, **eligibility for relevant existing devolved benefits, in particular Adult Disability Payment and Carer Support Payment in their current form, should be considered as passports for reserved elements in the UK benefits systems.**

“Like everyone else in this position I'm scared. Getting any benefits is hard and an unpleasant experience and having to go through the process time and again is wearisome.”

(Unpaid carer during consultation with NCOs)

The UK Government should pause proposals and undertake full and transparent engagement with the Scottish Government to reduce the impact of proposals on disabled people and unpaid carers in Scotland and on the budget available to the Scottish Government.

Whilst the Scottish Government has indicated that they do not intend to make corresponding changes to restrict the daily living element of Adult Disability Payment, which is welcome, changes to the PIP daily living component in England and Wales will have unwelcome consequences for Scotland in future.

The changes proposed by the UK Government will affect the Scottish budget, with the Scottish Government noting that the impact shows a forecast reduction for PIP of £380million and for Carer's Allowance, £49 million^{ix}. This will leave a significant gap in the social security budget of the Scottish Government and Social Security Scotland and will bring unenviable choices over other spending areas which could have additional impacts on unpaid carers and those they support.

If, as the Government has indicated, existing claimants are protected, this initial reduction will be lower but will build over a longer period as new individuals become sick, disabled or take on a caring role.

However, across this consultation and its proposals, understanding of the implications for devolution and the consultation with the Scottish Government and other devolved administrations appears to be an afterthought.

The NCOs strongly urge that this **engagement with the Scottish Government must be expedited and be open and transparent** to support the Scottish Parliament, unpaid carers, those they care for and representative organisations to have clear visibility of and involvement in future choices.

Key facts about unpaid carers:

- Every day nearly 1000 people will become unpaid carers, 44% of whom will be in paid employment^x.
- Most unpaid care is provided by people aged 50–64 who are most likely to have the most intense caring roles^{xi}.
- Many unpaid carers miss out on support as they do not recognise themselves as unpaid carers. More than half (58%) take a year or more to recognise themselves as an unpaid carer, with 26% taking five years or more^{xii}.
- 28% of unpaid carers and 65% of those in receipt of a Carer Element within income related benefits such as UC live in poverty.
- Two thirds (65%) of unpaid carers are struggling to afford the costs of electricity and gas, with 28% cutting back on essentials like food and heating to make ends meet^{xiii}. One in eight (12%) have skipped meals and 11% not eaten for a day to make ends meet^{xiv}.
- Two thirds (617%) of BME unpaid carers suffer financial difficulties due to caring with 52% cutting back on food or utility bills to make ends meet^{xv}.
- 60% of adult unpaid carers (352,403) are currently in the workforce, 22% of whom care for 35 hours or more a week.
- At some point in their career, a third (34%) of working age unpaid carers have given up work, 28% have reduced hours and 15% have taken a lower paid or more junior role because of their caring responsibilities^{xvi}.
- Recent research on BME unpaid carers found that half (48%) were “not in paid work”, which impacted family income and savings for the future^{xvii}.
- 28% of unpaid carers reported that they had bad or very bad physical health and 36% bad or very bad mental health^{xviii}.
- A third (33%) of unpaid carers in Scotland are disabled (compared to 24% of non-carers)^{xix}.

Caring and poverty

These reforms will increase poverty amongst unpaid carers. The majority (97%) of unpaid carers in the NCOs surveys said that the proposals would make it harder for them to manage financially.

More than a quarter (28%) of Scotland's unpaid carers already live in poverty. They are 56% more likely to live in poverty, and 60% more likely to live in deep poverty than non-carers^{xx}. With intense caring responsibilities and a lack of social care support, many unpaid carers are forced to give up paid work to care or reduce working hours which often results in an even higher risk of living in poverty. Nearly six in ten unpaid carers in receipt of Carer Support Payment and 65% of those in receipt of a Carer Element within income related benefits such as UC are living in poverty^{xxi}. In addition, some groups of unpaid carers face even higher levels of poverty eg. 67% of BME unpaid carers in Scotland report financial difficulties due to their caring role, with 45% being on household incomes of below £20,000^{xxii}.

Two thirds of unpaid carers (65%) are struggling to meet the costs of electricity and gas. More than a quarter (28%), including 41% of those on Carer Support Payment and 50% of those in receipt of a Carer Element within income related benefits are cutting back on essentials like food and heating to make ends meet^{xxiii}. A third (35%) are struggling to afford the cost of food, with one in eight (12%) are skipping meals and a similar proportion (11%) not eating for a whole day to make ends meet^{xxiv}. Worryingly, as many as one in ten unpaid carers are cutting back on support services^{xxv}.

A third (33%) of unpaid carers in Scotland are disabled (compared to 24% of non-carers)^{xxvi}. Two thirds (39%) of disabled unpaid carers in State of Caring 2024 were struggling to make ends meet, with 38% cutting back on essentials and 14% using foodbanks to make ends meet^{xxvii}.

Poverty is not confined to those unpaid carers who are not in paid employment, with research showing that one in six unpaid carers currently in paid work are struggling to make ends meet, and over a quarter (26%) are cutting back on essentials such as food and energy^{xxviii}.

Caring and health

These reforms will increase the impact of caring on the physical and mental health of unpaid carers. It is worth noting that they are already increasing anxiety and stress amongst unpaid carers. The majority (97%) of unpaid carers in the NCO surveys said that they felt stressed or anxious when thinking about the UK Government's proposals.

Research over many years has identified the significant and detrimental impact of caring on mental and physical health. Carers Scotland's most recent research found that 28% of unpaid carers reported bad or very bad physical health, rising to 49% for those who were struggling to make ends meet. The impact on mental health was even greater, with 36% of unpaid carers reporting bad or very bad mental health, with a worrying 59% of unpaid carers who were struggling to make ends meet reporting such poor mental health. Levels of poor mental health had increased by 28% from the results of similar research 12 months earlier^{xxix}.

Earlier research found that more than half (54%) of unpaid carers said their physical health had suffered because of caring, with 20% suffering an injury in their caring role^{xxx}. Carers Scotland's previous research^{xxxi} found that four in ten (41%) of unpaid carers are unable to access services for their own health because of the demands of their caring role. Some communities of unpaid carers experience even greater poor health. Six in 10 (60%) of BME unpaid carers in recent research by MECOPP and Oxfam Scotland said their physical health had suffered because of caring, with 40% saying their mental health had suffered. Only one in 4 said they have access to any support that allows them to take a break from caring.

The Scottish Fiscal Commission in its report on Fiscal Sustainability^{xxxii} recognises that the impact of caring on health carries risks not just to individual health but also the economy and the sustainability of

public services, saying that “*the age demographic of unpaid carers and the fact that this age group has seen the largest increase in reporting of a health problem or disability which limits day-to-day activities between 2011 to 2022 poses a risk in the future. This is the age group that carries out most unpaid care who may not be able to do so because of their own activity-limiting health problems*”. These proposals do nothing to provide a cohesive approach to the challenges unpaid carers and our respective countries face now and in years to come.

Caring and paid employment

These reforms fail to recognise and support the right and ability of unpaid carers to remain in or return to employment. As noted earlier, 97% of unpaid carers in NCOs surveys about the reforms said that the proposals would make it harder for them to provide care. For unpaid carers in paid employment this could make challenges in juggle work and care even more difficult.

In Scotland, 352,403 unpaid carers are currently in the workforce, representing 60% of the adult caring population. Of these 83% (303,928) are employed and 13% (48,475) are self-employed. A significant number of unpaid carers are balancing substantial caring roles with their employment. One in five (22%) of adult unpaid carers currently in the Scottish workforce are caring for 35 hours or more each week^{xxxiii}. Carers Scotland’s research^{xxxiv} found that 40% of unpaid carers in *full-time employment* were caring for 35 hours or more, the equivalent of another full-time job.

Managing such caring responsibilities alongside paid work impacts the ability of unpaid carers to remain in paid employment. At some point in their career, a third (34%) of working-age carers have given up work, 28% have reduced hours, and 15% have taken a lower-paid or more junior role because of their caring responsibilities^{xxxv}. For unpaid carers in BME communities in Scotland, the 2022 census shows they are more than twice as likely to be unemployed than the general population^{xxxvi}.

The peak age (45-54) for unpaid caring responsibilities also coincides with the peak of a professional career, making the negative impact on earnings even greater. The impact of caring is not just immediate; the loss of career progression compounds the negative effects of caring on earnings and on retirement income. Because caring tends to fall disproportionately on women, the difficulty of combining paid work and unpaid care further deepens existing income inequalities between genders.

Reducing unpaid carers’ ability to be in paid employment has potentially devastating consequences for both their short-and long-term finances but also for the economy. Employers lose talented and skilled workers and have increased costs to recruit and retrain, and the economy sees productivity impacts and the economy could be affected by ill-health and unpaid carer to the staggering cost of £37 billion a year. As many as one in three workers within the NHS is an unpaid carer.

Furthermore, earlier research^{xxxvii} asked unpaid carers who are not in employment what, if anything, might prevent them from returning to paid employment. Nearly two-thirds (64%) said that being unable to find suitable replacement social care was a fundamental issue to overcome. For some, the reliability of this replacement care had directly contributed to giving up paid work to care. **The reforms propose nothing to build a stronger foundation of social care to support the employment opportunities of both unpaid carers and disabled people.**

The same research into unpaid carers and employment found that nearly two-thirds (62%) of unpaid carers identified that only limited hours of employment were possible due to caring responsibilities, and unpaid carer focus groups identified many individual health barriers for unpaid carers, including their own physical disabilities and poor health. **The reforms propose nothing that will support disabled unpaid carers facing disadvantages of reduced social security and poorer health alongside their caring responsibilities.**

Conclusion

Every day around 1000 people become unpaid carers^{xxxviii}. With Scotland's population ageing and more people living longer with multiple health conditions, and at the same time, health and social care systems struggling to meet demand, the numbers of people caring continues to grow and unpaid carers continue to face greater demand, at the same time as support too often reduces.

Whether in the paid workforce or not, the contribution of Scotland's unpaid carers is invaluable to the Scottish economy. The unpaid labour that carers in Scotland provide saves the economy £15.9 billion each year, a figure that has increased by 19.4% since 2011. They are the backbone of Scotland's health and social care system and without them the system would simply collapse.

The plans set out in the Green Paper, even with existing claimants protected, will hit unpaid carers, disabled people and their families very hard now and in the future. This will entrench existing inequalities, particularly relating to intersectional issues that many unpaid carers face, including gendered inequalities, disability and for those from BME communities. The NCOs again urge the UK Government to pause the reforms completely, fully consult and consider all impacts and costs before working with disabled people and unpaid carers to make the social security system and services to provide support into employment as effective as possible.

*“... we are already struggling to make ends meet at the end of the month.
Our disabled son shouldn't have to know that the government doesn't even consider him deserving
of enough money each month to feed and clothe him.”
(unpaid carer during consultation with NCOs)*

National Carer Organisations 30 June 2025

About the National Carer Organisations

The National Carer Organisations (NCOs) are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, MECOPP, Shared Care Scotland and the Scottish Young Carers Services Alliance (SYCSA). Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The NCOs aim to achieve this through the representation of unpaid carers and giving them a voice at a national level. We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, representing the views of unpaid carers and focusing our collective efforts on achieving improvements in areas of legislation, policy and practice that are of greatest concern to unpaid carers.

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