

# Disabled People, Unpaid Carers and the Cost of Living Crisis: Impacts, Responses and Long Term Solutions



28 October 2022

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# Summary

The rising cost of living, driven in particular by dramatic increases in the cost of energy, has resulted in crisis for the sections of our society at highest risk. Disabled people, people living with long term conditions, and unpaid carers are more likely to find themselves both with higher bills and with less ability to pay.

Even after government intervention, energy bills will have doubled compared to last year, and low-income families are estimated to be almost £800 short of covering the range of increased costs including food and other utilities. From engagement with disabled people, people living with long term conditions, and unpaid carers, through partnership with Disability Equality Scotland and a discussion event held during Challenge Poverty Week, it was clear that the overwhelming majority did not think cost of living support had gone far enough.

For disabled people, people living with long term conditions, and unpaid carers, adequate support to cover their energy bills could be the difference between remaining healthy at home or needlessly ending up in hospital, to the detriment of their health and dignity, and at greater cost to public finances. As an essential public health intervention, targeted emergency social security payments could make a significant difference, as a form of preventative spending. Longer term action to rebalance how we approach the economy and public finances and uphold human rights is necessary to address the root causes of the crisis.

The ALLIANCE recommend that:

- The Scottish Government prioritise emergency cost of living payments.
- £400 top-up payments be issued to anyone receiving a disability payment, and anyone receiving either Winter Heating Payment or Carer's Allowance, costed at approximately £372 million.
- Additional support packages should be implemented as appropriate, determined on the basis of ease of access, targeting, and adequacy.
- The UK Government uprate reserved payments in line with inflation.
- Both Governments take actions to address the root causes of the crisis by investing in renewable energy, energy efficiency and poverty reduction measures, and funding these from additional windfall taxes.
- In the longer term, the approach to budgeting and the economy should put wellbeing and human rights at the centre, not GDP and profit.

# Introduction

Throughout 2022, people across the United Kingdom have increasingly felt the pressure from rising costs of living. Much of this is rooted in a sharp increase to energy bills, which by October had the potential to be almost three times as high as they had been a year previously.

The steep increase in energy costs has been a key driver of inflationary pressures across all areas of household expenditure. Every part of our economy is fundamentally reliant on energy, whether to power and heat premises, operate manufacturing and production equipment, transport goods and people, or run administrative systems. When energy prices increase, that means the price of almost all other goods and services end up increasing too, further straining the affordability of basic essentials, on top of the direct increase in domestic energy bills.

In common with the third sector as a whole, the Health and Social Care Alliance Scotland (the ALLIANCE) have serious concerns about the unequal impacts of the rising cost of living on the people and organisations we support. In particular disabled people, people living with long term conditions, and unpaid carers are likely to be more heavily impacted by rising energy costs, whether due to spending more time at home, having less physical tolerance for lower temperatures, the need to power and charge assistive technologies, or to keep medications at a safe temperature.

As these groups are also already more likely to have lower incomes and higher expenditure, they are at greater risk of struggling to keep up with the consequential increases in prices for food, clothing, transport and other utilities. In addition to impacts on individuals, there is also wide concern about the organisational and business impacts. Many, especially smaller, third sector organisations who support groups at highest risk are worried they will not be able to afford heightened running costs. It is clear that additional, targeted and comprehensive cost of living support is required, beyond what the UK and Scottish Governments had announced at the time this report was written.



## Scoping a response

In this context, the ALLIANCE recognised the need to develop specific, evidenced calls for immediate support, as well as longer term actions that would address the root causes of the crisis. The ALLIANCE has worked to scope options and develop proposals, informed by discussions with other organisations to this end.

Over the summer, we met with partners from across the third sector to discuss the situation, share ideas, and inform a way forward. The organisations we met included ALLIANCE members and wider partners, Citizens Advice Scotland, Energy Action Scotland, Disability Equality Scotland and the Poverty Alliance. Two key themes emerged from these discussions;

**That ensuring individuals could afford their energy bills was absolutely essential**



**That in line with best practice for anti-poverty measures, the ideal form of support would be direct cash payments**



## **Context: domestic energy bills**

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At the end of 2021 the price cap for the average household bill stood at £1,277 per year.<sup>1</sup> Although communication surrounding the price cap has often given the impression that it is the maximum amount payable, it is specifically calculated with regards to the average bill. Many households including those at high risk were already paying above the average, for example due to the additional energy costs for assistive technologies used by disabled people. In addition, the cap for pre-payment meters remains higher than for direct debit customers, though for brevity only the direct debit figures are directly quoted in this section.

From April 1 2022, average prices increased to £1,971, an increase of over half (54%).<sup>2</sup> At this point, it was already widely anticipated that Ofgem, the regulator responsible for setting the cap, would announce a further significant increase at the next sixth-monthly review period. This led to an initial package of UK Government-led support, which is outlined in a later section.

In due course, Ofgem made two further significant announcements regarding the cap. Firstly, they confirmed that from October 1 2022, the cap would increase to £3,549.<sup>3</sup> This represented a staggering 81% increase from the April cap, and a 178% increase from the end of 2021. In other words, the average household could expect to be paying almost three times as much by the end of 2022 as they had a year previously, whilst households with above-average costs would be faced with commensurately greater increases.

The second was that the energy price cap would be reviewed quarterly rather than every six months.<sup>4</sup> That meant the expected next date for an increase to the cap became January 2023. Independent modelling suggested that by that point the cap could increase to £4,150,<sup>5</sup> a further 17% higher than the October cap, and a total of 225% relative to end of 2021 prices. Following these announcements, the UK Government put in place plans to directly address energy bills.

## **Context: cost of living support**

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In direct response to the cost of living crisis, the UK and Scottish Governments have developed a range of support measures. This section only discusses direct cost of living supports, but it is important to recognise the positive impact of indirect supports such as the welcome increases to the Scottish Child Payment. Due to the comparatively limited nature of revenue raising and borrowing powers available to the Scottish Government, most of this support is in the form of three packages from the UK Government.

The first package announced in February 2022<sup>6</sup> was limited, consisting of only two measures. One of these was a £200 discount to all households on energy bills in October. However, this discount was in the form of a loan, and would have been paid back in £40 instalments over the following five years. The other was a £150 rebate for anyone in a property within Council Tax bands A to D in England and Wales. This was considered a blunt and untargeted measure and when the Scottish Government chose to replicate it, it was criticised by anti-poverty organisations, including the Poverty Alliance.<sup>7</sup>

It rapidly became apparent that this support was nowhere near sufficient, and the UK Government announced a larger package in May 2022.<sup>8</sup> This doubled the energy bill discount to £400 and made it a true discount rather than a repayable loan. It also introduced three targeted cost of living payments:



The third, and most recent at time of publication, package was announced shortly after Liz Truss took office as Prime Minister in September 2022. This was directly targeted at energy bills, with the 'Energy Price Guarantee' introducing a new cap for domestic bills equivalent to £2,500 on the average bill.<sup>9</sup> This was initially intended to be in place for two years, but in a subsequent announcement the scheme only was confirmed to be guaranteed until the end of March 2023, with any future support subject to a Treasury review.<sup>10</sup>

In addition, business bills, including for third sector organisations, are to be fixed for six months from October 2022, by around half of what they had been expected to cost via the 'Energy Bill Relief Scheme'.<sup>11</sup> As the political climate remains unsettled at time of publication, the longer term persistence and extent of these relief schemes is unclear.

Despite these measures, low-income households were still left facing a significant gap between their income and additional costs. The Joseph Rowntree Foundation estimates that, when including the sum of all means-tested payments, low-income families are still £783 short of what is needed to cover their costs.<sup>12</sup> Although these figures do not account for the disability payment, they also do not account for the additional costs disabled people were already paying. Nonetheless, this offers a useful guide rule as to the level of support that may be required by many specifically as a result of the cost of living crisis.

# Developing an ALLIANCE response

To further develop proposals three key considerations were kept in mind:

- Ease of access; that support should be provided in the most accessible manner possible, minimising administrative burden on both the people receiving support and the bodies delivering that support.
- Targeting; that support should go to the groups who are most impacted by the crisis, particularly disabled people, people living with long term conditions, and unpaid carers.
- Adequacy; that support should contribute substantially and meaningfully to addressing financial shortfalls.

## Prescribing energy: work with Disability Equality Scotland

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The ALLIANCE's policy development work started with the concept of 'prescribing energy' – that people could receive money directly from the NHS to cover the cost of their energy bills. This idea came from the principle that in addition to the impacts on wellbeing and dignity, the financial costs of treating and keeping someone in hospital because they were allowed to get to a needlessly critical point are substantially greater than paying their bills so they can stay warm, operate assistive equipment, and maintain medication at useable temperatures.

In effect, this would be preventative healthcare spending. However, questions remained about how this would be administered, how eligibility would be determined, and whether payments would be adequate. Before proceeding with in-depth development of the prescribing energy idea, it was important to engage with those most impacted to determine whether this was the right track.

In partnership with Disability Equality Scotland (DES), the reaction to this idea was explored using one of their weekly polls, running in the week beginning 22 August 2022. By coincidence, this was just after a leaked proposal in the media suggested the UK Government was considering a similar approach, which would have been administered by GPs.<sup>13</sup> This may have impacted how individuals responded to the poll.

In the poll, a total of 97% of respondents said they were "very concerned" about the rising cost of energy. However, when asked whether they thought prescribing energy would be a useful way to help with the cost of bills, only 17% said yes, whilst 83% said no.



Many of the respondents said they did not think that GPs were equipped to deal with the issue, pointing to overwork, the risk of damaging the patient/doctor relationship, and lack of GP training in what was effectively a welfare issue. One particularly striking response read “I think it is wrong to medicalise a social issue like this.” Instead, many responses highlighted the need for a cash-first approach using social security, the fact that social security agencies already had data that could be used to target payments, the possibility of a social tariff for people receiving disability payments, and the need for direct government intervention in the energy market.

These findings were invaluable to the ALLIANCE team to further develop a response. They re-emphasised the importance of a dignified, cash-first approach to support, and the inadequacy of using the healthcare system to address socio-economic issues, even those which could have eventual health impacts.

## Emergency social security payments

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Following the report on DES’ findings, it was agreed that the basis for an emergency response should be the social security system, though still centred on the principle that this was preventative spending to help protect health and wellbeing. As such, the team then began to investigate existing social security payments which it would be possible for the Scottish Government to top-up. Two key routes were identified for delivering these payments.

The most obvious route to get additional support directly to disabled people and people living with long term conditions would be via Disability Payments. These include Child Disability Payment/Disability Living Allowance, Adult Disability Payment/Personal Independence Payment and Attendance Allowance. Prior to the 2021 Scottish Parliament election, it was estimated around 533,000 people in Scotland were receiving these payments.<sup>14</sup>

Winter Heating Payment (previously referred to as Low Income Winter Heating Assistance) is a new Scottish payment which replaces the UK Government’s Cold Weather Payment. As this payment is targeted at people on lower incomes, as disabled people, people living with long term conditions, and unpaid carers are more likely to be, it would be another way to deliver targeted support. An automatic payment of £50 will be made in February 2023 to households receiving income related payments, including Pension Credit and Universal Credit, estimated to number 400,000 in Scotland.<sup>15</sup>

The ALLIANCE suggests the value of emergency payments should be £400, which would mean anybody eligible through both routes would receive £800. It was considered likely that many disabled people in particular would be in both categories, and that the resulting £800 payment would cover the gap identified by the Joseph Rowntree Foundation. This would come at a total cost of approximately £373 million to the Scottish Government, an important but substantial additional resource investment that would likely be reliant on consequential arising from UK Government spend.

Referring to the three key considerations listed earlier, this approach scores well against each measure. By topping up existing social security payments, the people eligible are already known and can be paid without the need to apply for support, or for Social Security Scotland to create new administrative structures for a separate payment; this addresses the issue of ease of access. As payments would go to individuals receiving other disability and income related payments, we can be sure they would go to those with greatest need; thus addressing

the issue of targeting. Finally, the suggested payment was set at a level that would, for a large number of recipients at least, close the main gap identified by the Joseph Rowntree Foundation; and that addresses the issue of adequacy.

It is recognised that these two payments will not reach every household struggling with their energy bills, and in some cases may not cover the entirety of the cost of living gap. However, the specific payments chosen to top-up would enable a well-targeted approach, with minimal additional administration, and would be a significant help to a very large number of disabled people, people living with long term conditions, and unpaid carers. This should form one part of a wider package of comprehensive supports to a range of groups and individuals impacted by rising cost of living, rather than being the totality of further emergency support this winter.

## Other emergency responses

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Additional responses to address the pressing emergency of this winter were also put forward. In immediate response to Ofgem’s announcement on the proposed October price cap increase, the ALLIANCE called for that increase to be immediately reversed by the UK Government.<sup>16</sup> That was partially, but not wholly, addressed by the energy price guarantee the UK Government announced in September.

It was also suggested that individuals should be given the flexibility to use unused Self-directed Support (SDS) budget to pay their energy bills. Where someone has unused SDS budget, given the importance of a well-heated home to their health and wellbeing, paying energy bills from it should be considered essential care, and likely in line with personal outcome plans that aim to enable people to live independently and well. This would be in line with SDS Standard 12, which states that “Personal budgets can be spent in any way that is legal and that is related to meeting agreed personal outcomes”.<sup>17</sup> Importantly, this should be a matter of individual choice – nobody should be forced to spend their budget in this way as a substitute for other support.



## Long term responses

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Beyond the short term emergency of winter 2022-23, it is important to recognise both the deeper roots of the crisis, and the need for longer term action to address those root causes. The current crisis is not entirely new, but is driven by and exacerbates existing inequalities, as the impacts fall hardest on those already struggling. Poverty and inequality, even when alleviated or reduced after the fact, can cause long term damage to mental and physical health, with the potential for impacts that are still felt for years after the acute crisis is resolved.

The need for a significant change in how we approach public spending, public services, and the budgeting process has become especially apparent. Action to address poverty, particularly issues such as inadequate and unaffordable housing, food insecurity, and the adequacy of the social security system in a sustainable manner are essential. The national budget should be approached not simply from the perspective of GDP, debt and costs, but instead by centring human rights, gender equality, and the wellbeing economy.

Finally, further windfall taxes should be levied as appropriate to ensure that accidental and opportunistic profits arising from the current or any future crisis are redistributed to counter the impacts. For already wealthy individuals and corporations to benefit from record profits whilst the least well off in society are living in poverty, struggling to heat their homes and put food on the table is fundamentally unjust. This proposal was advocated by several respondents to our poll with Disability Equality Scotland.



# Event: 'Cost of Living Crisis: Impacts, Responses and Long Term Solutions'

## Disabled people, unpaid carers and the cost of living crisis

Impacts, responses and long term solutions



6 October 2022 • 2.00pm - 3.30pm • Online

Email [event@alliance-scotland.org.uk](mailto:event@alliance-scotland.org.uk) to register



Having developed initial detailed proposals for emergency support, and thoughts on longer term solutions, the ALLIANCE wanted to hear directly from people affected, and from organisations supporting them. Together with DES, a joint event 'Disabled People, Unpaid Carers and the Cost of Living Crisis: Impacts, Responses and Long Term Solutions' was held on 6 October, as part of the Poverty Alliance's Challenge Poverty Week 2022.

The event included two short presentations from DES and the ALLIANCE and two discussion sessions, one focussed on lived experience and emergency payments, and the second on long term solutions. 30 people attended the event.

## Lived experience context: DES

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James Davidson, Communications and Research Manager at DES, opened his presentation with a reminder of the specific additional energy requirements for disabled people, including needing to stay warm for health, energy for charging assistive equipment, and safe storage of medication. He then outlined the findings from a number of DES' weekly polls.

An early poll in April had asked whether there was enough support in place to address the rising cost of living. 97% of respondents said there was not. Some respondents were already beginning to report that they were unable to afford the costs of heating and were turning it off, despite the negative impact of doing so on their health.

Following the announcement of the more detailed package of support in May, 96% of those polled stated they did not think it went far enough to cover the costs of their energy bills. Particular concerns were raised from responses to this poll that unpaid carers who were not receiving a means tested benefit but who were receiving Carers Allowance were not eligible for the cost of living payment.

In the August poll which had asked about prescribing energy, described earlier in this report, 97% of respondents stated they were "very concerned" about the rising cost of energy, with most of the remaining 3% "quite concerned". One respondent explained the direct and extremely serious impact rising costs were having on them:



I have a small, travel powerchair for hospital visits and a larger one for shopping. They both take 4 hours to charge up. My bath raiser takes 16 hours to charge! I cannot manage without them. I feel cold all the time and dread the winter now with my Arthritis. I will not be able to afford the bills.

James shared one final poll from September, which followed the UK Government's energy price guarantee. Only 11% of respondents felt the guarantee would be effective, whilst 71% stated it would not be, and 18% were unsure. In written responses, members of DES felt it did not fully address the large increases over the previous year and noted that disabled people would be paying above and beyond the £2,500.

From responses to these polls, James concluded with three themes that had come up repeatedly in detailed responses. Firstly, that there should be targeted support through the social security system. Secondly, that there should be direct government intervention in the energy market, including even to the extent of nationalising energy companies. Thirdly, that support and information relating to it should be available in accessible formats, noting that there was very little information available in formats such as British Sign Language (BSL) or Easy Read.

## Emergency payments and long term solutions: the ALLIANCE

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In this presentation, the ALLIANCE shared the policy development context and detail outlined in earlier sections of this report. Policy and Information Officer Allan Faulds explained how the policies on emergency payments had been developed, with reference to the energy price increases and the Joseph Rowntree Foundation's research into the cost of living gap. Following this Jane Miller, Academy Programme Manager, took participants through some of the principles to guide possible longer term actions.

### Discussion: lived experience

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During the first discussion session, some attendees explained how rising energy bills and the wider cost of living had affected them personally. Some stated that they did not normally discuss their personal circumstances, but felt they needed to share their current experiences and chose to do so within the group. This may indicate they felt that they were in a safe space to share, which included peers who would understand, or the extent of the impact on these individuals. The ALLIANCE are extremely grateful to everybody who shared their experiences and recognise that doing so can be a difficult and upsetting process.

Reliance on powered mobility equipment such as wheelchairs was repeatedly mentioned, with one participant stating that they were scared to charge theirs due to the spiralling costs, impacting on their independence. At least two attendees had wet rooms at home and had found related costs had increased substantially, to the extent that one person had stopped using it and was instead washing themselves with wet wipes to save money.

A number of contributors also highlighted the impact of cold temperatures on their conditions – for example due to having difficulty regulating their body temperature, or by worsening chronic pain. Some had already begun to go without heating and were reporting that they were cold and shivering as a result. For one individual energy costs were so unaffordable that they had even begun cutting back on lighting, to the extent that they said they would have been sitting in the dark if they were not attending the meeting..

One participant, reflecting on the range of additional energy costs, felt they did not have an option to use less energy for these things, and that cutting back was impacting their human rights. Another was already in energy debt and was worried about being having their supply terminated entirely.

Cutting down on food was another common experience. Some attendees were prioritising other people over themselves, for example their children or a person they cared for. Two separate attendees said that all they had had to eat that day was a biscuit with a cup of tea – one of them added they generally only had one meal a day.

The pre-existing issue of the "Disability Price Tag", where disabled people already face additional costs whilst also facing limitations on their income, was also raised from two different angles. One disabled attendee added that the gap in income versus expenses arising from the cost of living was simply added to the already existing gap, which was never adequately filled. Research from Scope was highlighted, showing that on average disabled people face extra costs of £583 per month, with one in five facing extra costs of more than £1,000 per month.<sup>18</sup>

This had been exacerbated by the pandemic, as social care packages had been reduced and left more people to have to manage by themselves. Another participant, who was an unpaid carer, explained that the additional costs to support the disabled person they cared for consumed more income than their household had, and felt the cap on earnings for unpaid carers to be eligible for Carers Allowance was particularly unjust. Individuals also spoke about the impact the cost of living was having on the delivery of care. For example, staff retention challenges resulted in long gaps and uncertainty between carers. We heard of instances when people were “put to bed at 4pm” or left sitting in a chair all day.

Attendees who were not themselves disabled, living with a long term condition, or an unpaid carer, but who worked for third sector organisations supporting these groups, also shared some of the impacts they were aware of. Carer organisations were fielding calls from unpaid carers who could not afford heating or food, but who also could not access the Scottish Welfare Fund, and were looking for referrals to food banks or other sources of emergency funding.

Some charities themselves were unable to afford to heat their buildings, or to meet rising demand for their services. This was reported to be having a knock-on effect on the people using those services, including unpaid carers who were relying on them for very short breaks. The impact on mental health was emphasised, as so many people are now worrying about how they will make ends meet.



## Discussion: emergency payments

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During the first discussion session, participants also shared their views on the proposed emergency payments. There was a clear consensus that the proposals were sound, and that the payments identified for top-up made sense and were well targeted. The fact the payments would be automatic was appreciated, with one participant expressing their relief they would not need to go through the process of sending an application from their phone if they were to receive payments that way.

Some participants did query as to whether it would be appropriate or fair for some people only to receive one £400 payment, whilst others would receive two for a total of £800. They wondered whether this might result in inequalities. They were also mindful that even targeted payments would see some people who need support slip through the net.

A few attendees also raised points about the social security system more generally. The need to discuss the stigma surrounding social security was mentioned, after one participant had noted there was a sad and annoying feeling about being judged as a “scrounger” for receiving social security payments, even for people who are in work. This is something the ALLIANCE have previously highlighted in our evidence to the Cross Party Group on Poverty’s inquiry into poverty related stigma.<sup>19</sup>

Some suggestions for additional forms of emergency support were highlighted through the discussion. The possibility of directly supplying people with blankets and gloves to keep them warm, and LED lights to save on energy bills, was raised by one participant. Support services within communities such as pantries and warm banks were also mentioned, though particularly in light of COVID-19 it was felt warm banks would not be suitable for everyone, for example people with autoimmune conditions.

In addition, there has been specific concern about allowing warm banks to become the norm in the same way food banks have, with both representing a failure of governments to ensure the availability and affordability of basic necessities.

## Discussion: long term solutions

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The second discussion session considered the wider and longer term issues necessary to tackle the roots of the crisis. One participant stated they felt the cost of living crisis should be treated with the same level of focus and action as the pandemic, and that it was a form of public health crisis too. However, there was a feeling of being unseen by those in power, who did not understand the realities facing people on lower incomes, or disabled people, people living with long term conditions, or unpaid carers. Participants wanted the government to speak and listen to people with lived experience, and act accordingly.



Building on what had arisen from the first session, the issue of tackling stigma associated with social security was again emphasised. Anger was expressed about comments made by leading UK Government ministers which suggested people “choose” to receive social security in lieu of working. The fact social security payments had been frozen for a number of years despite prices, particularly for food, continuing to rise during that period was considered deeply unfair. Other issues relating to social security included the need to increase payments in line with inflation, as well as issues of payment cliff-edges and tapering, where UK Government encouragement to find work can actually leave people worse off.

Another key thread of discussion considered the specific issues surrounding energy itself. Investment in renewables, such as solar panels to help individual households reduce energy bills, as well as in energy efficiency measures such as insulation and alternative forms of heating rather than from gas was broadly supported. For household level investment, it was felt this should be supplied through at-cost loans to those who can afford it, and completely free to people on lower incomes. The fact there used to be grants for these kinds of things, but there is not anymore, was mentioned as a failing.

In terms of the energy providers themselves, some agreed with the idea of additional windfall taxes. Another suggestion was that rather than directly increase taxation, they could be required to spend 50% of their profits on green energy. The issue of prepayment meters being a more expensive form of energy was also raised, and it was felt there should be a way to reduce tariffs, for example a specific tariff for disabled people, and to do so without requiring a move to direct debit payments.

Other items that came up in less detail throughout the discussion included the need for further, accessible information on how to save energy and money; making care work more visible, understood and appreciated, potentially via a new National Performance Framework outcome on care; community building, with people going door to door to check on neighbours; the availability of suitably diverse and nutritious food, including hot meals; and addressing housing costs such as mortgage rates which are becoming unaffordable.



# Conclusions

The cost of living crisis is deepening poverty and inequality across the UK. For disabled people, people living with long term conditions, and unpaid carers in particular, many were already living in poverty and excluded from society before the current crisis, which has only made their circumstances worse.

Participants at the ALLIANCE and DES hosted event during Challenge Poverty Week shared their own, often harrowing, experiences, including being unable to charge powered wheelchairs and thus being stuck at home, finding the costs of showering and bathing unaffordable, not having enough to eat, and poor mental health. Poverty is not simply a crisis of income, but of dignity and human rights.

These personal experiences, combined with recent research on rising costs, make it absolutely clear that whilst the cost of living packages announced so far are welcome, they have not gone far enough to support members of our society most at risk. It is essential that additional, targeted cash payments are made to help people through this winter and prevent a public health emergency. The costs of providing this support will be substantially less, in both human and financial terms, than needlessly allowing people's health to deteriorate to the point at which they need acute, hospital-based interventions.

Feedback from the event confirmed that the ALLIANCE's proposed emergency payment approach was seen as viable and appropriate, although with a recognition that it would not solve the crisis by itself, and that it could be expanded to more clearly support unpaid carers, offering it to the 81,000 people receiving Carer's Allowance, though it's unclear how many of those would already be receiving disability or winter heating payments. Although there were some concerns raised about the fairness of some people receiving £400 whilst others would get £800, the fact a number of participants pointed to the additional costs for disabled people suggest that it is reasonable to offer one payment which is specifically targeted at people receiving disability payments.

Additional points relating to immediate social security priorities were also helpful and taken on board. In particular, the need for reserved social security payments to be increased in line with inflation is both apparent and was a timely contribution to discussion, as the UK Government have been debating internally whether to do so, or to offer a lower increase in line with wages, which would be insufficient.

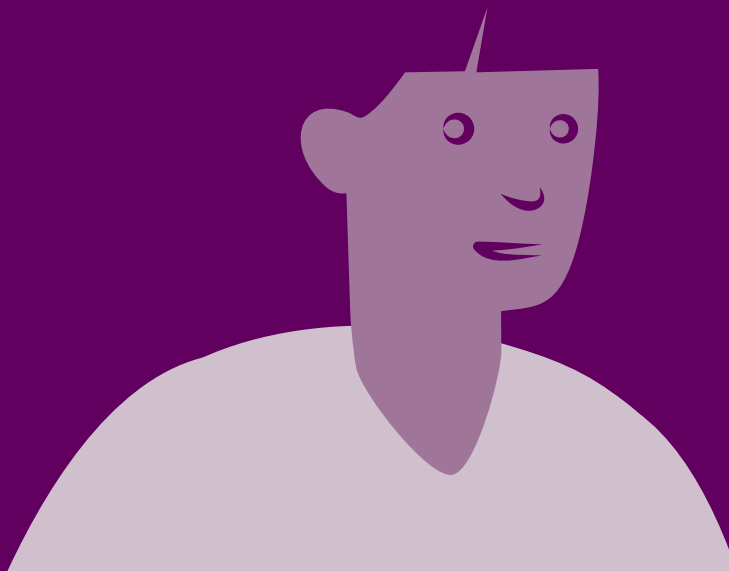
In the longer term, we must address the root causes of this crisis, and prevent it from recurring. Investment in our energy system, with more renewables, more energy efficient homes, and fairer tariffs should be a priority for both governments, as too should destigmatising and investing in the social security system, ensuring adequacy and availability of a range of payments as a right. More widely, we should aim to build an economy that centres human rights and wellbeing over GDP and profit.

# Recommendations

## Emergency payments and responses

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- Emergency social security payments to address the cost of living crisis should be the first priority for any consequential spend the Scottish Government has available arising from UK Government cost of living support packages.
- A £400 top-up payment should be issued as soon as possible to two eligible groups; anyone receiving a disability payment, and anyone receiving either Winter Heating Payment or Carer's Allowance. This is costed at £372 million for the disability payments and Winter Heating Payment elements.
- People who would be eligible in both groups should receive both payments for a total of £800.
- Additional support packages should be considered as appropriate, determined on the basis of ease of access, targeting, and adequacy.
- The UK Government should uprate reserved social security payments in line with inflation.



## Long term solutions

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- Both Scottish and UK governments should commit to engaging directly with those most impacted in co-designing and shaping dignified responses to crisis and ongoing policy development including disabled people, people living with long term conditions and unpaid carers.
- Both governments should invest in transforming the energy system, including by greater investment in renewables and alternative heating sources, and in energy efficiency measures provided via long term loans to those who can afford them, and freely to those who cannot.
- Both governments should work to destigmatise social security, presenting it instead as a fundamental human right, and should ensure the adequacy and accessibility of payments.
- Government and society should work towards a rebalancing of our economic approach, which currently prioritises profit and GDP growth, but should instead have human rights and wellbeing at the centre.



## About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.



## About the Health and Social Care Academy

The Health and Social Care Academy (the Academy) is an ALLIANCE programme that helps drive positive and significant change in Scotland's health and social care, through the voice of disabled people, people living with long term conditions, and unpaid carers. The Academy's 'Five Provocations for the Future of Health and Social Care' was created based on the vision from the Think Tank of Scottish senior leaders from across the public sector, third and independent sector leaders, and people who use health and social care services.



# References

- 1 Ofgem, 'Price cap to increase by £693 from April' (February 2022), available at: <https://www.ofgem.gov.uk/publications/price-cap-increase-ps693-april>
- 2 As above
- 3 MoneySavingExpert, 'Energy bills to rise a sickening 80% from October' (August 2022), available at: <https://www.moneysavingexpert.com/news/2022/08/energy-bills-to-rise-from-october-for-millions-as-new-price-cap/>
- 4 Ofgem, 'Ofgem confirms changes to the price cap methodology and frequency ahead of new rate to be announced later this month' (August 2022), available at: <https://www.ofgem.gov.uk/publications/ofgem-confirms-changes-price-cap-methodology-and-frequency-ahead-new-rate-be-announced-later-month>
- 5 Cornwall Insight, 'Cornwall Insight comments on the announcement of the October Price Cap' (August 2022), available at: <https://www.cornwall-insight.com/cornwall-insight-comments-on-the-announcement-of-the-october-price-cap/>
- 6 UK Government, 'Millions to receive £350 boost to help with rising energy costs' (February 2022), available at: <https://www.gov.uk/government/news/millions-to-receive-350-boost-to-help-with-rising-energy-costs>
- 7 The Guardian, 'Scotland's 'timid' £150 council tax rebate disappointing, say charities ' (February 2022), available at: <https://www.theguardian.com/society/2022/feb/10/scotlands-timid-150-council-tax-rebate-deeply-disappointing>
- 8 UK Government, 'Cost of living support factsheet: 26 May 2022' (May 2022), available at: <https://www.gov.uk/government/publications/cost-of-living-support/cost-of-living-support-factsheet-26-may-2022>
- 9 UK Government, 'Energy bills support factsheet' (September 2022), available at: <https://www.gov.uk/government/publications/energy-bills-support/energy-bills-support-factsheet-8-september-2022>
- 10 HM Treasury, 'Chancellor brings forward further Medium-Term Fiscal Plan measures' (October 2022), available at <https://www.gov.uk/government/news/chancellor-brings-forward-further-medium-term-fiscal-plan-measures>
- 11 UK Government, 'Energy Bill Relief Scheme: help for businesses and other non-domestic customers' (September 2022), available at: <https://www.gov.uk/guidance/energy-bill-relief-scheme-help-for-businesses-and-other-non-domestic-customers>
- 12 Joseph Rowntree Foundation, 'Joseph Rowntree Foundation highlights the gap in support that remains for people on low incomes after Liz Truss energy announcement' (September 2022), available at: <https://www.jrf.org.uk/press/joseph-rowntree-foundation-highlights-gap-support-remains-people-low-incomes-after-liz-truss>
- 13 The Guardian, 'GPs could prescribe money off energy bills under Treasury plan' (August 2022), available at: <https://www.theguardian.com/society/2022/aug/21/gps-could-prescribe-money-off-energy-bills-under-treasury-plan>
- 14 Citizens Advice Scotland, 'Scotland should aim for 'world-leading' disability assistance system, says expert coalition' (2021), available at: <https://www.cas.org.uk/news/scotland-should-aim-world-leading-disability-assistance-system-says-expert-coalition>

- 15 Scottish Government, 'New benefit to help with winter fuel bills' (June 2022), available at: <https://www.gov.scot/news/new-benefit-to-help-with-winter-fuel-bills/>
- 16 The ALLIANCE, Twitter (August 2022), available at: <https://twitter.com/ALLIANCEscot/status/1563154974447570950>
- 17 Social Work Scotland and Scottish Government, Self-directed Support Framework of Standards, including practice statements and core components (2022), p. 16, available at: <https://www.gov.scot/publications/self-directed-support-framework-standards-including-practice-statements-core-components/>
- 18 Scope, 'Disability Price Tag' (2019), available at <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag/>
- 19 The ALLIANCE, 'ALLIANCE response to poverty-related stigma inquiry' (March 2022), available at: <https://www.alliance-scotland.org.uk/blog/news/alliance-respond-to-povety-related-stigma-inquiry/>

