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## **Impact of energy costs on people who are disabled or living with health conditions**

Summary report of findings from a series of discussion workshops

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**Consumer  
Scotland**  
Luchd-Cleachdaidh Alba

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## Introduction

### Context

The cost of energy has been significantly higher than the historical average while consumers are also facing wider cost-of-living challenges. Households where someone is disabled or living with a health condition are at greater risk of affordability challenges in this context due to typically having higher costs and lower incomes compared to households without a health condition. For many this includes paying more for energy as they have an increased need for heat to manage their condition and may also rely on electrical medical, mobility or assistive technology equipment.

Consumer Scotland is the statutory and independent body for consumers in Scotland. It works across a range of sectors, including energy. Its [Energy Tracker survey](#), published in autumn 2023, showed that disabled people and people with health conditions are more likely to report affordability challenges compared to those without a condition, and that these challenges are negatively impacting many aspects of their lives, including their mental and physical health.

### Objectives

To better understand the energy requirements and associated energy costs that disabled people and those with health conditions experience, Consumer Scotland commissioned Collaborate Research to design, arrange, conduct and report on at least two discussion workshops involving a mix of relevant organisational representatives, along with people with lived experience of a disability or health condition, including carers. The specific aims of the workshops were to:

1. Explore how energy costs impact different types of disabled people and people with long-term or life-shortening conditions and identify the priority issues in terms of energy affordability
2. Discuss how to better support disabled people and people with health conditions with their energy costs and address their affordability challenges
3. Identify any future research, data gathering or analysis required to address the priority areas identified in the workshops and how that could be taken forward, ensuring it is underpinned by expertise and the lived experience of disabled people and people with health conditions

Three workshops have now taken place to discuss these themes.

### Face-to-face workshop in Edinburgh

The first workshop was conducted face-to-face in Edinburgh, between 10:30 and 14:30, on 11th December 2023. Amongst the 25 attendees at this event were:

- Representatives from 13 organisations which included:
  - Charities representing or working with disabled people and/or people with health conditions

- Organisations with an interest in energy and/or general consumer issues

Some organisational representatives who took part also have lived experience of being disabled or living with a health condition.

- 11 energy consumers who are disabled, living with a health condition or a carer for someone who is. These consumers have experience of a range of different conditions including physical disabilities, learning disabilities, mental health conditions, and complex health needs.

This workshop included a mix of plenary sessions (involving all participants), and facilitated smaller group discussions. The running order is summarised below.

<h2>Running order</h2>		
Approx. timing	Type of session	Focus of session
10:45	All together	Summary presentation of existing evidence
11:00	Smaller groups	Discussion of how energy costs impact disabled people and those with health conditions
11:45	All together	Sharing feedback from each breakout group
<b>12:00</b>	<b>Lunch break</b>	
12:45	Smaller groups	Discussion of how to better support disabled people and those with health conditions with energy costs
13:15	All together	Sharing feedback from each breakout group
13:30	Smaller groups	<i>[Optional for those who are able to stay]</i> Discussion of additional evidence needs to ensure future support is well designed and targeted
14:00	All together	Sharing feedback and discussion of next steps
<b>14:30</b>	<b>End of workshop</b>	

A number of measures were applied to ensure this workshop was conducted in an accessible, inclusive and ethical way. For example, we asked participants to identify their individual accessibility needs at the recruitment stage so we could respond to them in the organisation and running of the research. On the day, we arranged the break-out groups so that most people with lived experience of disability, having a health condition or caring responsibilities were together in order that they would feel comfortable to share their experiences. We also applied the social model of disability to how the discussions were framed, which is based on identifying and addressing the structural

barriers and additional detriment faced by those with disabilities and long-term health conditions due to the way society is organised.

### **Online workshops**

In addition, two smaller online workshops were subsequently held in January 2024 with people who were unable to attend the face-to-face event. These followed a similar running order but were shorter in duration (between 1 and 2 hours). A total of 9 participants attended these online workshops.

### **This report**

In this report we have sought to summarise the range of opinions shared by participants, which were based on personal experience, direct feedback from service users and in some cases survey data. We have aimed to highlight how prevalent these opinions were and have also included selected quotes to provide a flavour of views expressed.

A list of the specific organisations represented in the workshops is provided in Appendix A.

## Headline findings

There was consensus in the workshops that disabled people, people with health conditions and their family carers are at greater risk of energy affordability challenges compared to those without such conditions. This was attributed to three linked factors:

- The high cost of energy combined with their high usage needs, especially for heating but also for a variety of other reasons related to people's individual requirements including powering medical equipment, having paid carers in the home etc.
- Limited opportunity to reduce their energy use without experiencing detriment
- Having generally lower incomes and a higher cost of living

While each of the above factors was perceived to apply to all disabled people, people with health conditions and their carers to some extent, certain groups were felt to be particularly affected due to the intersection of their disability or health condition with other factors. These could include:

- Socio-economic characteristics such as older age, coming from an ethnic minority background or living on very low incomes
- Energy usage circumstances, such as if they have a prepayment meter, are reliant on electricity or alternative fuels for heating, or live in a less energy efficient home

A number of different impacts associated with energy affordability challenges were identified by participants. At the extreme end, such challenges were perceived to increase the risk of severe illness and even death. In addition, there were reports of people cutting back on essentials, as well as negative effects on their mental health, relationships and social isolation.

There was a general view that existing financial support measures available to disabled people and people with health conditions are insufficient. This was attributed in part to the lack of specific provision made for the additional energy costs many such people incur, both directly due to their conditions as well as to additional characteristics or circumstances of some people have (sometimes referred to as intersectionality). It was also pointed out that with much of the support available the onus is on the individual to identify what they are eligible for and apply for it. This means that some people risk missing out on support that they are entitled to.

Both social tariffs (which exist for some other services but not currently in energy) and the Warm Home Prescription (which is currently being trialled) were seen as potential ways of better supporting disabled people and those with health conditions with their energy costs. In addition, there were calls for more promotion of available support measures as well as active signposting, support with applications and efforts to destigmatise benefits claiming.

The prevailing view in the workshops was that a lot of evidence already exists about how energy costs impact disabled people and people living with health conditions, and that the priority now is to get policy makers to act on this.

However, some knowledge gaps or opportunities for further evidence collection were identified, including:

- Bringing available evidence together in one place
- Quantifying the differential energy costs experienced by people with different conditions and intersectional characteristics
- Comparing current benefit provision to the costs associated with being disabled, living with a health condition or caring for someone who is
- Making the economic and social case for providing better support with energy affordability to disabled people, people living with health conditions and family carers

There was broad agreement that people with lived experience need to be heavily engaged in future decision making in this space, in keeping with 'nothing about us without us'.

## Session 1: Presentation of existing evidence

In the first workshop session, participants were presented with a summary of findings on energy affordability for disabled people and people with health conditions, drawn from Consumer Scotland's most recent research and as well as relevant reports from other organisations. The key statistics provided included:

### From Consumer Scotland's most recent Energy Affordability Survey<sup>1</sup>:

- 68% of disabled people reported rationing energy use (compared with 56% of non-disabled people)
- 51% of disabled people were unable to heat their home to a comfortable temperature (compared with 35% of non-disabled people)
- 48% of disabled people reported that energy affordability issues had an impact on their mental health (compared with 26% of non-disabled people)
- 41% of disabled people found it difficult to keep up with their energy bills (compared with 24% of non-disabled people)
- 40% of disabled people reported cutting back on their food in order to afford their energy bills (compared with 24% of non-disabled people)
- 38% reported that energy affordability issues had impacted their physical health (compared with 17% of non-disabled people)

### From other research conducted by other organisations:

- In a survey undertaken by Marie Curie<sup>2</sup>, 84% of healthcare staff observed terminally ill patients struggling to afford their energy bills
- In a survey undertaken by Inclusion Scotland<sup>3</sup>, 77% of disabled people said that they were going without or cutting back on essentials
- Euan's Guide<sup>4</sup> surveyed 7,000 disabled people and found that 68% had cut back on their energy use
- A submission from Energy Action Scotland to UK Parliament<sup>5</sup> referred to polling which found that 13% of those reliant on electrical medical equipment were reducing their use of this equipment

<sup>1</sup> Consumer Scotland (2023) [Energy Tracker data tables autumn 2023](#)

<sup>2</sup> As reported in National Energy Action and Marie Curie (October 2023) [Taking the Temperature of NG6](#)

<sup>3</sup> Inclusion Scotland (2022) [Cost of Living Crisis - What's the Impact on Disabled People](#)

<sup>4</sup> Euan's Guide (2023) [Cost of Living Crisis](#)

<sup>5</sup> UK Parliament Committees (2023) [Written Evidence Submitted by Energy Action Scotland to the Cost of Living Enquiry](#)



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- Carers Scotland<sup>6</sup> reported that unpaid carers are also experiencing unprecedented financial pressures
- Citizens Advice Scotland<sup>7</sup> reported that prepayment meter customers, who are often disabled, are at particular risk of self-disconnection because they can't afford to pay for their energy

Participants then discussed how these findings align their own lived and/or professional experiences.

<sup>6</sup> Carers Scotland (2022) [State of Caring 2022](#)

<sup>7</sup> As reported in [Scottish Housing News](#), 21 February 2023

## **Session 2: Impact of energy costs and priority issues**

### **2.1 What are the main energy requirements and associated costs of disabled people and people with health conditions?**

Workshop participants generally felt that many disabled people and people with health conditions have an increased need for a warm home compared to those without conditions. This is particularly to help manage pain but could also be due to having a condition which makes it difficult to maintain an adequate body temperature or is exacerbated by humidity or damp. They may therefore need heating on at a higher temperature and for longer periods, especially if they are less mobile or housebound. Given this, heating was generally perceived to be the main contributor to household energy bills of disabled people and people with health conditions. An organisational representative estimated that having an enhanced heating need increases the energy bill by approximately 60% compared to a standard heating regime.

Another major use of household energy was identified to be electrical medical, mobility and/or assistive technology equipment among those reliant on such devices. For example, one participant said that the person she cares for uses an oxygen concentrator, nebuliser and suction as well an electrically powered bed, chair and hoist, all of which need to be constantly on charge. Another referred to their organisation's analysis which found medical equipment costs can increase energy bills by up to a third. A further participant reported that their organisation has seen clients unable to run such equipment due to the energy costs.

There may be a number of further enhanced energy usage needs depending on each person's individual circumstances. Some examples provided included a need for:

- Frequent hot baths or showers to manage pain
- Enhanced lighting due to a vision impairment
- More frequent washing of clothes and bedding

Having carers in the home reportedly adds further to household energy use and if paid carers are involved, the home becomes effectively a workplace with a health and safety obligation to ensure staff feel warm and comfortable.

### **2.2 What are the main energy affordability challenges faced and factors influencing this?**

Workshop participants generally believed there to be three linked reasons for disabled people, people with health conditions, and their carers being at greater risk of energy affordability challenges compared to those without such conditions or caring responsibilities:

- High cost of energy combined with high usage needs

- Limited opportunity to reduce energy use
- Generally lower incomes and a higher cost of living

### **High cost of energy combined with high usage needs**

Not surprisingly, the main contributor to these energy affordability challenges was generally perceived to be the current high cost of energy, particularly given the enhanced energy needs that many disabled people and people with health conditions have, as reported in the previous section.

A number of participants felt that electricity standing charges are often higher in Scotland. One organisational representative referred to one of their service users running up energy debt while in hospital for an extended period due to the standing charges even though power was not being used at the time. People with lived experience also referred to high standing charges, including for using prepayment meters, which they found difficult to afford.

It was widely expected that energy prices will increase again which was of great concern to participants.

### **Limited opportunity to reduce energy use**

Several people with lived experience said that they personally ration or cut back on their energy use, including only heating certain rooms, turning the thermostat down, limiting the time the heating is on, or not using central heating at all. However, it was generally acknowledged that this may not be possible for some people, such as those with complex or severe conditions. In addition, it was expected that those with progressive conditions or who have received a terminal diagnosis may need to use more energy over time. For example, an organisational representative referred to research by Marie Curie<sup>8</sup> which shows that a terminally ill person's energy bill can rise by 75% after their diagnosis.

In addition, an organisational representative said that energy bills are found by consumers to be very complex so it may not be clear even to those able to change their energy use what actions they could be taking to reduce their bills. This participant also felt that energy suppliers are not helping their customers sufficiently to understand the energy efficiency measures that are available to them.

### **Lower incomes and higher cost of living**

An organisational representative in one of the workshops referred to a finding from the Scottish Household Survey<sup>9</sup> that household incomes for disabled households tend to be lower than those who are not. In addition, it was generally felt that disabled people and people with health conditions need to pay a premium in many areas of life. One example provided was the rising cost of private transportation to and from medical appointments (due to higher fuel costs) as using public transport

<sup>8</sup> Marie Curie (2023) [One Charge Too Many](#)

<sup>9</sup> As reported in Transport Scotland (2019) [Findings from the Scottish Household Survey - Demographic Characteristics of Disabled people in the Survey](#)

may not be feasible for them. It was also mentioned that local authorities are increasing the client contribution required towards the cost of care.

Means tested benefits were widely perceived to be insufficient for disabled people, people with health conditions and their carers partly due to these being based on gross income and not taking into account the extra costs that they may incur. Consequently, some people reportedly do not have enough to cover essential bills and are running deficit budgets.

Similarly, benefits available to carers were regarded as insufficient to cover essential expenses, as the caring role reportedly comes with a range of additional costs and can also affect the carer's ability to take on paid employment, thus limiting their income.

While all disabled people and people with health conditions, along with their family carers, were perceived to be at risk of affordability challenges, workshop participants felt that for certain groups these risks are particularly high due to the intersection of their disability, health condition or caring responsibility with other characteristics or circumstances:

- People from minority ethnic groups, who are more pre-disposed than their white counterparts to some long-term conditions, more likely to be unpaid carers and more likely to be living on low incomes
- Older people who are more likely than younger people to have health conditions and/or caring responsibilities, and may also be living on lower incomes
- One-income households, particularly sole parents
- People unable to work due to their condition or caring responsibilities, and are fully reliant on benefits
- People who need to pay for care, particularly if they have extensive care needs (which will also mean that they are likely to be heavy energy users)
- People who use electricity for heating, as the cost of heating with electricity is often considerably higher than gas
- People using prepayment meters who pay higher unit prices for their energy use
- People living in rural areas who are more likely to be paying higher energy costs, especially if they are not on the gas grid and reliant on an alternative fuel (this may include people from the Gypsy/Traveller Communities who are more likely to live off-grid in chalet or mobile accommodation)
- People living in less energy efficient homes, who may have little opportunity to make energy efficiency improvements (e.g. if their home is rented, they are living in a property where there are restrictions on what can be changed, or due to the financial cost or disruption associated with making changes)

## 2.3 What are the effects of these energy affordability challenges?

A number of different types and degrees of impacts associated with energy affordability challenges were identified by the workshop participants.

At the extreme end of the scale, having a cold home was perceived to put disabled people and people with health conditions at greater risk of severe illness and even death. For example, one participant referred to a Marie Curie study<sup>10</sup> which found that 90,000 people die in poverty every year in the UK. It was also reported that the excess winter mortality rate in Scotland is now increasing.

Participants also mentioned the following potential impacts of energy rationing and/or struggling to pay for energy used:

- Negative financial impacts, including the risk of arrears or reduced ability to afford other essentials, including healthy food, physical therapies etc.
- Negative effects on physical health, including increased pain and fatigue if they are unable to heat their home sufficiently
- Negative effects on mental health, including depression and/or anxiety, both for people living with conditions and those who care for them
- Negative effects on relationships with family members and/or paid carers, which could be under greater strain due to the affordability challenges being experienced
- Increased risk of social isolation, e.g. if they are unable to charge mobility devices in order to get out of the home or if their income or mental health are a barrier to participation in society

The following quotes illustrate some of the detrimental effects referred to both by organisational representatives and people with lived experience:

*"I get really cold, but I cannot afford to turn the heating on and if we ever do turn the heating on, I clock watch, you know, it's on for 30 minutes and then it's off. I'll sit there suffering from chronic pain, with my legs going stone cold and my back killing me."*

*"We've been hearing stories where there might be someone choosing to prioritise feeding or heating for someone they were caring for over themselves, and also people saying that they weren't able to do things like charge powered wheelchairs. One woman was saying that she specifically felt that this was a significant breach of her human rights because she wasn't able to get out of her home and participate in society."*

*"My youngest wouldn't come to the house because it was too cold. It impacts on relationships, on having a life at home, which then impacts on your mental health."*

<sup>10</sup> Marie Curie (2022) [Dying in Poverty](#)

*"Energy costs can mean you can't afford other things that would actually help you maintain your mental health, like taxi fares, so you can't get to community groups or just kind of general socialisation. That has an impact on [mental] health because people become more isolated."*

*"We saw a lot of impact on people reducing contact with family, with friends, with their communities, stopping to use their car or transport, and that has impacted on their independence. It's also meant that people are spending a lot more time at home, and as a result of spending more time at home actually needing to use more energy."*

## Session 3: Addressing affordability challenges

### 3.1 What are the issues with current support measures?

#### Insufficient to meet rising costs

The consensus view among workshop participants was that existing financial support measures available to disabled people, people with health conditions and carers are insufficient given the current energy prices and the general cost of living. They mentioned that some types of support (e.g. the Energy Bill Support Scheme) were rolled back at a time when energy prices were set to increase further, and it is felt that others have not kept pace with cost of living rises. Some specific comments about this included:

*"Benefits should cover your essentials. That's what your benefits are. You should have this essentials guarantee, that it covers your bills and it covers your food, the minimum of everything that a human being needs, but it's just not the case. And why are benefits not going up in line with other costs? Westminster knows and the Scottish Government knows this is the case but nothing changes."*

*"The Scottish Government's Winter Heating Payment for people on benefits is now guaranteed £55 but that's nothing compared with how much costs have gone up."*

There were also specific comments made about the perceived inadequacy of Carers Allowance. The weekly rate in the UK is reportedly far less than is paid to carers in other countries<sup>11</sup>, and the full allowance is not available to people receiving State Pension or to most carers who remain in paid employment due to the weekly earnings limit applied. One participant commented:

*"Why on earth is it so low here? It's so imbalanced, what carers are providing compared to what they're getting back."*

#### No specific provision for differential energy costs

Another problem with existing support measures, and reason for their insufficiency, was perceived to be that there is not specific provision made for the additional energy costs many disabled people, people with health conditions and their carers incur. This omission was felt to particularly apply to current means tested benefits which are based on gross income and therefore do not differentiate based on actual costs that people in different circumstances incur. As one participant put it:

*"It's not a singular, homogenous experience that people have, it changes depending where you live and whether you've got gas for your heating or you've got electricity will make a huge difference financially, but it's the same level of financial support. And it's not based on net income so even if your expenditure [on energy] is considerably higher, because of the*

<sup>11</sup> The Republic of Ireland was mentioned as a comparison. The maximum weekly rate there ranges from [248 to 429 Euros](#), whereas in the UK the maximum rate is £77.

*consequences of your condition, it's not looked at. It's not proportionate, the support has been provided does not recognise that differentiation despite knowing it to be true."*

Some participants also specifically mentioned that NHS rebates for electrical medical equipment do not cover many types of equipment currently being used and, even where provided, the amount provided does not fully cover the costs associated with their use.

One organisational representative said that they perceived the lack of provision for additional energy costs is not in keeping with the Scottish Government's Fuel Poverty Strategy which includes recognition of enhanced heating regimes for disabled people and people with health conditions, and a new Human Rights bill in Scotland which includes a right to a healthy environment.

Another organisational representative made the following comment on this theme:

*"We really do feel that disabled people are being under-supported and are currently at a risk of being under-prioritised for government programmes, because they're not fully considering the impact that the current energy costs dimension of the cost-of-living crisis is actually having on disabled people, despite having large amounts of evidence to show this. We feel strongly that support is not being provided on a fair basis and that probably government isn't fulfilling its requirements under the Equalities Act."*

A related issue perceived by one organisational representative is that the current fuel poverty calculation mainly focuses on energy used for heating and lighting, and doesn't take into consideration other energy uses. As such, they felt that it underestimates fuel poverty amongst disabled people and people with health conditions, as well as those who pay for more energy for other reasons. This participant made the following comment:

*"Those that make the decisions don't actually see all the components they just see heat, light and that's it, that they don't think about the washer and the dryer and then the other bits of equipment, and also the actual energy efficiency of the home, because you could have the same situation but you're living in a different house or living in a colder area."*

### **Complex system meaning that eligible people potentially miss out on support**

In addition, it was pointed out by several organisational representatives that much of the support available requires individuals to identify what they are eligible for and apply for it. This was felt to pose particular challenges for some disabled people or people with health conditions who may be unwell, fatigued and/or digitally excluded. In the words of two workshop participants:

*"It's an overly complicated benefit system and it's stressful to make a claim. They may be overwhelmed by their condition and carers are overworked and underpaid already."*

*"A lot of disabled people have missed out because they haven't got access to online services and I think there's something really important about how do we deliver the levelling up of this situation because it needs to be accessible for everyone."*



People with lived experience concurred with this view, referring to how difficult it was for them to navigate the system and how they relied on peer support, including to tell them about what was available and how to apply for it.

There was also a perception that the benefits system is often regarded as hostile which can be a deterrent to potential claimants:

*"The benefits system makes you feel like you're not supposed to receive something so people are worried that if they get something they might have to pay it back and get into more financial trouble. A lot of people say that they don't have the time or the energy to fight for what they're entitled to."*

## 3.2 How could support be improved?

### Ensuring benefits are liveable

A lot of the discussion focused on the social security system generally and ensuring benefits enable disabled people, people with health conditions and their carers meet the costs of living. In the words of one participant:

*"We can play around the edges and give grants to people, and that's better than nothing, but really benefits need to be reviewed and increased so they're liveable."*

There was specific mention of the pilot in Scotland of a 'Basic Income' which is an 'unconditional, non-withdrawable income for every individual as a right of citizenship'<sup>12</sup>.

In the case of carers, it was suggested that a second non-means tested part of the Carers Allowance should be introduced that all family carers get access to in order to offset their costs. There was also perceived to be a strong argument for taking account of the value to society of the unpaid caring work being undertaken. It was mentioned that a non-means tested 'participatory income' for family carers is currently being discussed in the Republic of Ireland<sup>13</sup> which it was felt should also be considered in the UK.

### Appropriate targeting that considers both income and usage costs

Overall, participants supported the provision of targeted financial support in order to focus available funding on those in most need. They generally felt that targeting should consider both people living on low incomes and those who need to consume more energy as this quote illustrates:

*"It's about knowing when to be universal and when to be targeted with support. Some of the cost-of-living support has been very poorly targeted. Universalism can be good, and it can be quick and easy to provide, but it's more beneficial to do things that are targeted at those in most need."*

<sup>12</sup> Basic Income Scotland (accessed Feb 2024) [What is Basic Income?](#)

<sup>13</sup> Family Carers Ireland (2023) [Towards a Participation Income for Family Carers](#)

However, it was also acknowledged that determining the most appropriate targeting could be challenging, particularly where to draw the line in terms of who should be supported. Discussing this was quite an uncomfortable conversation to be part of for some participants. For example, one participant commented that:

*"Regulators and suppliers struggle to define who's most deserving in this space. People for whom a minute's loss of energy would cause irreparable harm are obviously the top group and no one would argue about that. But not many people are in that position and beyond that you quite quickly get into bigger groups who are also in need and the effect would be detrimental. I wouldn't want to be the one who sets the line."*

### **Specific support measures**

There was considerable support for energy suppliers providing social tariffs<sup>14</sup> in the future, as some suppliers of other services (e.g. broadband) currently do.

There was also interest in the Warm Home Prescription<sup>15</sup>, which is currently being trialled in some specific settings, as a potential future measure for providing support to vulnerable people.

In addition, some participants suggested that there should be:

- An increase in the level of the Scottish Government's Winter Heating Payment
- A widening of the scope of the Winter Fuel Payment to cover disabled people, people with health conditions and carers aged under 65
- Further NHS contribution towards the cost of electrical equipment for people with high medical needs
- More investment in social housing and to increase the energy efficiency of homes
- Action from suppliers to make it easier for disabled consumers and those with a health condition to transition from a prepayment meter to a credit meter if they wish to (in order to benefit from lower standing charges and, importantly, also reduce the risk of self-disconnection)

### **Efforts to increase take-up of available support**

It was felt to be imperative to increase take-up of benefits that people are eligible for. In order to achieve this, it was felt that there should be more automated application of support to eligible people (as identified through the benefits system or otherwise) to avoid people having to claim for them.

For support measures which continue to require claiming, there were calls for more promotion to increase awareness, help with applications and efforts to destigmatise claiming. There were also suggestions for better signposting of available support, including by energy suppliers through the

<sup>14</sup> Scope (19 Jan 2023) [The Social Tariff on Energy Explained](#)

<sup>15</sup> Energy Systems Catapult (accessed Feb 2024) [Warm Home Prescription](#)

Priority Services Register, as well as more warm referrals between organisations to identify and support claimants. In the words of two participants:

*"It would be good to have a better tie up, as in when somebody is diagnosed with a particular illness, there should be an automatic route to this is how you get help, this is what you're entitled to."*

*"I feel like a warm referral network between organisations, where you're not expecting individuals to go to all of the different places but instead the local organisations get together to say 'who are these people that we're constantly we're seeing in our services?' and actually deal with some of their underlying issues."*

## Session 4: Additional evidence needs

The prevailing view in this workshop was that a lot of evidence already exists about how energy costs impact disabled people and people living with health conditions (from the DWP, Scottish Government, NHS and other sources), and that the priority now is to get policy makers to act on this. In the words of one participant:

*"There's a need for governments to realise that a lot of evidence exists and they just need to act on that evidence. Often there are these reviews and reports that say 'this is what we know to be the case, this is what you could do differently' and then nothing gets done, it just sits on the shelf gathering dust."*

Some participants felt that more research without action would reduce the willingness of people with lived experience to share their experiences and views in the future. These sentiments were expressed by the following participants:

*"What's the purpose of research if we're not seeing action taken? We ask people to engage so we can represent them the best we can. But there's only so often we can ask the same questions before people start feeling jaded and don't want to participate anymore."*

*"Up-to-date statistics are important but it's how we engage with decision-makers that's important. There's something problematic about consistently asking people to share really personal, private, sensitive information and it's not getting transferred into action."*

It was felt to be important that any further research has a clear strategic objective and adds to the evidence base rather than replicating what is already known.

That said, some specific evidence gaps or opportunities for research, data gathering or analysis were perceived by some participants:

### **Bringing the available evidence together in one place**

There was perceived to be a need for existing evidence from various sources to be synthesised, such as through a rapid evidence assessment, so it is together in one place and can more easily be drawn on. Two participants commented:

*"It's not so much the case that the data is missing but it's held by lots of different people, it's not in one central place."*

*"It's all coming from different angles. It's how we bring all the evidence together."*

### **Quantifying differential energy costs**

There was also a view expressed that more needs to be done to quantify the variability of energy costs incurred by people with different conditions, e.g. the costs required to power different types of electrical medical equipment or have carers at home, and how energy costs may change through different stages of progressive and degenerative conditions etc. The participant who raised this felt

that this analysis would help to quantify the real level of fuel poverty among disabled people and help government to determine what the appropriate levels of financial support should be.

However, another participant raised a concern that differentiating needs in this way could risk moving away from a social model of disability which would be a retrograde step:

*"My major worry with all of this is that it then medicalises disability when a lot of us have spent a lot of time trying to move us away from all of that. From a social model of disability perspective, it could put us back in that box."*

### **Comparing costs and benefit levels**

Related to the above, it was suggested that the costs associated with being disabled, living with a health condition or caring for someone who is be compared current benefit levels in order to demonstrate the size of the gap. In the words of one participant:

*"Whenever you look at social security benefits, I'm convinced that it's fairly random how much money people get, and it tends to be rather historic. At no point has anybody looked at the actual costs of running a household and the additional costs of being a carer. If somebody is disabled and the family income is coming from benefits, I can tell you that the average cost of living, your rent, your mortgage, your transport, your food, your heating will far short of the income that's coming in. And I don't think I've never seen that comparison actually been done before. It seems like such an obvious thing to say but the money they're getting is not enough."*

### **Making the economic and social case for providing better support**

In addition, an opportunity was identified to help make the case for better financial support with energy costs for disabled people and people with health conditions. This was envisaged to involve quantifying economic and social benefits of providing better support and, conversely, the increased costs in other areas, especially to the health service, if sufficient support is not provided. For example, two participants made the following comments:

*"The big challenge for preventative spend is that governments want to say we spent however many millions and therefore we saved this many billions. It's hard to follow that through on a short-term basis, getting the evidence to back that up."*

*"We need to look at what's the cost of not supporting it because we're talking about exacerbating impairments, we're talking about more GP time, more NHS time. We shouldn't be looking at it purely from a financial view but there's a big, big argument about how much money we could save by supporting people to live comfortably."*

However, some felt that there is already evidence in this area, such as regarding the costs of a cold home to the NHS.

### **Further specific suggestions**

Some participants also made the following suggestions for further research:

- Quantifying and profiling those with unmet needs, either because they have not claimed support they are eligible for or because they fall just outside the eligibility thresholds
- Identifying the barriers to take-up of support measures and exploring how to address these
- Evaluating current support measures to understand what is not working about them from
- Learning from other jurisdictions in terms of the support provided to people who are disabled, living with health conditions or caring for someone who is
- More piloting of potential solutions

### **How to involve people with lived experience**

Some experts by experience said that this was the first time they had an opportunity to provide their own personal testimony and they called for more focus on hearing directly from people with lived experience in this way.

However, other participants felt that there has been a heavy emphasis so far on collecting qualitative insights and opinion poll findings on personal impacts, and it was their view that these types of evidence may be losing salience with policymakers. This links to the earlier suggestions for further evidence collection to focus on 'harder' data, such as quantifying the additional energy costs incurred by people with different conditions or measuring the broader economic and social impacts of providing or not providing sufficient financial support. In the words of one participant:

*"I think in order to shift the mindset [from benefits to living income] we need to provide evidence, hard numbers, because, you know, I don't think [the government] listens to the emotional kind of argument in the same way."*

Despite these differences of opinion, there was broad agreement that people with lived experience need to be heavily engaged in future decision making in this space, in keeping with 'nothing about us without us'.

It was felt that it was important to reach a diverse cross-section of people who have experience of being disabled, living with a health condition or caring for someone who is. In particular, there were calls for more engagement with hard-to-reach groups and seldom heard voices, including to understand their barriers to accessing support, as mentioned previously:

*"Something we're always trying to work it out is how do we get more uptake? How do you reach communities who are not already identifying themselves as being potentially eligible?"*

This was felt to require more flexible and creative methods (e.g. going into communities, involving experts by experience as peer researchers etc.) in order to ensure effective engagement.

## Appendix - Workshop attendees

Representatives from the following organisations attended the workshops:

1. Carers Scotland
2. Carers Trust
3. Children's Hospices Across Scotland (CHAS)
4. Citizens Advice Scotland
5. Coalition of Carers
6. Disability Equality Scotland's Midlothian Access Panel
7. Disability Equality Scotland's West Lothian Access Panel
8. Enable Scotland
9. Energy Action Scotland
10. Health & Social Care Alliance Scotland
11. Inclusion Scotland
12. Marie Curie
13. MECOPP
14. Mental Health Foundation's Voices of Experience (VOX)
15. MND Scotland
16. MS Scotland
17. One Parent Families Scotland
18. Research Institute for Disabled Consumers (RiDC)
19. RNIB Scotland

Some of the organisational representatives who attended have lived experience of being disabled or living with a health condition.

In addition, the face-to-face workshop was attended by 11 energy consumers who are disabled, living with a health condition or a carer for someone who is.

We are grateful to all attendees for their participation.