

Stacked Against Us

Disabled people's poverty and the cost-of-living crisis

Inclusion Scotland's Conference Report 2023

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Introduction

A report about disabled people, poverty and the cost-of-living crisis. This report includes disabled people's lived experience and solutions for change. These changes must be made now.

Inclusion Scotland is the national Disabled People's Organisation. Our February 2023 Conference - Stacked Against Us - brought together disabled people and Disabled People's Organisations from across Scotland.

We talked about what is happening to disabled people as the cost-of-living continues to rise and we struggle to survive.

As disabled people, we are experts by experience. We know what changes are needed, and we must be included in making the changes.

Ahead of the Conference Inclusion Scotland surveyed disabled people about the impact of the cost-of-living crisis on our daily lives. Three-quarters of people who responded told us they were already going without or cutting back on essentials like food or heating.

You can read the report including plain text and Easy Read versions <https://inclusionScotland.org/home-page-news/cost-of-living-crisis-hits-disabled-people-hard-new-report-published>.

Our special thanks to Ben MacPherson Minister for Social Security and Local Government Scotland who answered delegates' questions, and to Lindsay Graham OBE, Deputy Chair of the Poverty and Inequality

Commission who shared her knowledge and insights about disabled people's poverty.

Finally, thank you to all our members who took part in the Conference.

Disabled people's poverty and the cost-of-living crisis

The situation for disabled people is horrendous.

Even before the impact of the cost-of-living crisis began to be felt by the wider population, disabled people and our households were already more likely to be living in poverty.

When the extra costs associated with disability are taken into account 28% of all people living in poverty are disabled people. Another 20% of people living in poverty live in households with a disabled person. This means that nearly half of all people (48%) living in poverty in the UK live in households with at least one disabled person.ⁱ

On top of rising costs for everyone, disabled people have extra costs to meet, and less income to meet these extra costs. The UK charity Scope reported that disabled people pay £583 per month for extra impairment-related costs. One-fifth (20%) of disabled people have extra costs of over £1000 per month. After paying for housing, these extra costs are equivalent to almost half of our income.ⁱⁱ

Our higher costs are to pay for things like extra energy, equipment and special diets. Extra energy is needed to keep warm enough to cope with ill-health conditions and pain, to stay mobile, and for things like additional laundry.

We also need extra energy to use lifesaving equipment like home dialysis machines. The costs to install,

maintain and power adaptations like hoists and stairlifts are high, even with the limited support that is available.

Meanwhile essential services like social care support, therapies, advice, and peer support are being reduced or cut entirely. We are isolated at home without the social care support we need to live our lives and councils are still charging for this essential support.

All this means we have less money to pay for other things and that we are forced to pay just to stay alive, live in our own homes and to be part of our communities.

We are 'worried sick' and living in fear of being stuck in a hospital, or forced to live in a care facility if we cannot meet these extra cost.

The Covid-19 pandemic has already pushed more disabled households into poverty and as disabled people, we are more likely to say that our finances have been negatively impacted by the pandemic. Disabled people who must still shield at home have simply been forgotten about.

We have lower income because we are less likely to be in work than people who are not disabled.

There is a disability employment gap and a disability pay gap between disabled people and non-disabled people which means we are less likely to be in work than non-disabled people, and when we are employed we earn less than them. The disability employment gap between disabled people and non-disabled people in Scotland is

31.2 percentage pointsⁱⁱⁱ and the disability pay gap is 18.5%. This is the largest gap among the 4 UK nations.^{iv}

The gap is getting smaller, but not small enough and not fast enough.

For those of us who do work, we earn nearly £4,000 less a year than non-disabled workers.^v

The pandemic has shown us that remote working is practical and possible but employers are increasingly telling workers to return to their workplace. These are often in expensive and inaccessible towns and cities where streetscapes have become unnavigable and accessible parking options reduced. Transport costs are rising and public transport is still inaccessible.

Disabled women especially are being pushed into lifelong poverty. Employment opportunities are fewer and we take up more caring roles for longer periods and then find we cannot return to work. On top of this, the high cost of child care makes employment prohibitive.

Help from social security is a human right. Disabled people got a smaller cost-of-living payment added to our disability benefits in 2022 than people on other benefits got. Those who claim Disability Living Allowance or Personal Independence Payment, and those who are on the Scottish Adult Disability Payment got £150.

Pensioners got double this amount (£300) and people on low-income benefits got £650.

Both the Scottish and UK Governments have committed to uprating benefits, including disability benefits, in April 2023 when they will increase them by just over 10%, the

September 2022 rate of inflation. This increase is welcome and will put much-needed cash into our pockets - but it is too little too late. By the time the uprating is introduced, benefit claimants will have faced several more months of rapidly rising prices.

Not every disabled person who needs benefits gets them, and proving eligibility is a horrible experience. For those who do get benefits, they are simply not enough to live on.

As prices continue to rise, the value of our income, whether from benefits or from employment, is rapidly getting less. Energy, transport, white goods, housing, food – the list is endless. Gas prices have gone up over 129% and electricity by over 66.7% in the year to February 2023^{vi}. Food costs increased above inflation to 16.9% in 2022^{vii}.

Food costs have risen nearly 20% in the past year, and food for specialist diets is even more expensive and harder to get. 1 in 10 households where someone is disabled has used a food bank^{viii} yet food banks, along with supermarkets and supermarket delivery services, are often inaccessible. The price of the cheapest items, which people in poverty rely on, has risen the most.^{ix}

On top of all this, there is less to fall back on. As disabled people, we have more debt and fewer savings.

Nearly a quarter of disabled households are behind on at least one bill and 40% of those owe money to a public

service. 30% of households where someone is disabled have no savings.^x

For disabled people with other protected characteristics, such as disabled women, black and minority ethnic disabled people the problems can be worse. Policy makers and service providers want to put us in the 'disability' box but do not understand, or have the willingness and capacity to understand, that we face multiple structural barriers and how to address them.

Disabled people living in rural areas also face additional barriers. Food in local shops is more expensive, whilst larger and cheaper shops are out of reach and inaccessible because transport options are few and expensive. Energy options are fewer and more expensive as some rural areas are 'off grid' for gas and people have to rely on oil deliveries or bottled gas.

Using the internet is often out of reach because it costs too much to pay for broadband and the assistive technology we need. Training and support to use the internet has fallen away and what remains is often inaccessible. This means we cannot 'shop around' for better deals for things like utility tariffs and we may struggle to access benefits and other support when we have to do it online.

Advice and support, from energy companies, health boards, and local authorities are not reaching us when we need it. We do not know where to turn to and when we do find help we encounter access issues. Disabled People's Organisations, which offer accessible services

and peer support, are poorly resourced and fighting for survival at a time when need is rising.

Quote 'It feels like we have to beg for support.'

All of this is having a negative impact on every part of our daily lives especially our physical and mental health, and on our futures. It comes on top of years of poverty, exclusion, inequality, UK welfare 'reform', and the stigma and is leading to us further from our rightful inclusion in society.

This report highlights disabled people's lived experience and solutions for change.

Solutions to disabled people's poverty and the cost-of-living crisis

Here's what disabled people said at Inclusion Scotland's Stacked Against Us Conference about experiencing poverty and the cost-of-living crisis and the solutions that need to be put in place now.

Solutions - The starting point

The starting point for all the solutions in this report must have the following values built in from the get-go.

Nothing about us without us - Decision makers and service providers must involve disabled people and our Disabled People's Organisations. This means more than just consulting us. It means co-producing the solutions with us. 'Nothing about us without us' is the motto of the disabled people's movement.

Quote 'Coproduction has to happen at the start, not as an afterthought.'

Prevention - A National Disabled People's Poverty Reduction Plan must be produced and implemented urgently. It needs to deliver action on the long-term causes of disabled people's poverty. Without lasting structural change, our lives will forever be at the sharp end of every new emergency.

Cash first and rights-based – The Scottish Government should deliver cash-first and rights-based approaches. This means realising our human rights in practice. It means putting cash in disabled people's pockets – 'not

offers of cooking courses and budget training’ – so that we do not face stigma and so that we can make the right choices for ourselves.

Knowledge – Public bodies should collect the right information and act on it. This must include information about the intersectional barriers for disabled women, black minority ethnic disabled people, older disabled people, and others.

Quote ‘We have a right to a seat at the table.’

Income from benefits

Disabled people are clear – support from benefits is a right, not a ‘handout’, but the income it gives us is not enough to live on.

Quote ‘The stigma needs to be removed for people accessing support and benefits.’

Quote ‘Benefits do not cover costs. Even the cost of running a mobile phone is prohibitive.’

Quote ‘If we can’t get jobs and our benefits are not enough, we can’t pay bills.’

Disabled people spoke about missing out on much-needed benefits because we do not meet the criteria when our income is just a few pounds above the threshold. The thresholds have not kept pace with the rising cost-of-living.

Quote ‘I tried for pension credit but £3 over the limit so don’t get anything.’

As disabled people, we often find it difficult to claim the benefits we are entitled to. One disabled person spoke being unable to afford public transport and the long walk to the job centre. Others spoke about the number of forms involved, how complex they can be and the amount of duplication involved.

Solutions – Income from benefits

Benefits should be available to disabled people who need them – the 20 metre and the 50% eligibility criteria for disability benefits should be expanded. (These rules mean that if you can walk more than 20 metres unaided or your impairment affects you less than 50% of the time, you may not be eligible for those benefits).

Benefits must keep pace with the rising cost-of-living – The UK and Scottish Governments should immediately uprate disability benefits by the current inflation levels.

Cost-of-living payment – The UK and Scottish Governments should make an additional cost-of-living payment to those on disability benefits to supplement the low payments made in 2022.

Employment

As disabled people we face many barriers to getting into, getting on, and staying in employment. Employers' attitudes and their unwillingness to make the adjustments to support us to work are still significant barriers to employment.

We also face discrimination and exclusion from education and training and have lower educational

attainment than non-disabled people. All of this serves to exclude us from employment and the income it brings.

Quote ‘Worked all my life...even those who haven’t been able to work have a lot to contribute to society. Why can’t disabled people be allowed to live?’

Disabled people spoke about losing work because of ill-health and how occupational health assessments are geared towards being ‘let go’.

Quote ‘People get labelled and it’s difficult to get back into employment.’

The Scottish Government published a Fair Work Action Plan to address barriers to employment and equal pay. Disabled People’s Organisations were involved in the Plan. This includes actions for disabled people who face intersectional barriers and people with other protected characteristics like black minority ethnic people and older people.

Solutions - Employment

Quickly close the disability employment gap and the disability pay gap – actions in the Fair Work Action Plan to reduce the disability employment and pay gaps and to remove the barriers to fair work for disabled people must be accelerated.

Energy

We all need energy in our homes. As disabled people, we have higher energy needs because we use life-saving equipment at home, like kidney dialysis machines, and to charge our equipment like powered

wheelchairs, hoists and stairlifts. We need to keep warm to manage our ill-health conditions.

Quote 'Turning lights off and going to bed to save on electricity.'

Learning disabled people spoke about the need to keep warm but being afraid to turn the heating on and highlighted that learning disabled people die on average 20 years younger than other people.

Because we cannot afford to pay our energy bills we are using less energy. This means trying to air dry clothes inside which makes our homes damp and is bad for our health. Disabled people also spoke about having to use a tumble dryer because they struggle to hang up clothes to dry and using the washing machine more because of incontinence or conditions like Parkinson's which can mean more spills on clothes.

We want to make things better but cannot afford to improve the energy efficiency of our homes. Some of the help available is difficult to find and does not cover every type of house or tenure.

Lots of disabled people spoke about how difficult and time-consuming it is to deal with energy suppliers. It is not a given that we will be added to 'priority' customer lists so that we can access extra support even though we need it because of our impairments. We struggle to get the right information and help from our energy suppliers in ways that are accessible to us.

Quote 'It's difficult to negotiate with big energy companies – they provide you with an arbitrary figure and say that costs will go up. It has an impact.'

Disabled people living in rural areas that have no gas supply have to pay high 'up-front' costs to get an oil delivery. If we cannot meet the costs then we have no heating.

Solutions - Energy

Cash to pay for energy for life-saving equipment - The Scottish Government and NHS Health Boards should work together, with Disabled People's Organisations to reimburse disabled people who have extra energy costs to run health equipment at home. This could follow the model of the Home Oxygen Service which reimburses energy costs for people who use oxygen concentrators.

Money for energy - The Scottish Government should increase the new Scottish Winter Heating Payment so that it keeps up with rising energy costs. The majority of the 400,00 households receiving the payment contain a disabled person and energy prices have doubled.

Support for disabled people who are 'off-grid' - The Scottish Government should increase funding to the Fuel Bank Foundation so that they can provide more support to disabled people who use 'off-grid' energy, including making emergency payments to people who are struggling to afford to pay for fuel or who are already in debt to fuel providers.

Enforcement action - Ofgem should take enforcement action where energy companies do not meet their

obligations such as action to ensure that disabled people are added to the Priority Services Register so that our energy supply is not cut off or where pre-paid metres are installed without our agreement or understanding of what this means for us.

Accessible information and communication – The Scottish Government could include specific information for disabled people in their cost-of-living support information.

Energy companies - should ensure that information, including bills, is readily available in alternative formats, and Ofgem should monitor this. Disabled people who need them should be offered metres that can give an audio output.

Social Care Support

Disabled people rely on social care support to live independent lives and to play a part in our communities. This support stopped abruptly from the start of the pandemic. Many disabled people are still waiting for their support package to be fully reinstated, or reassessed.

Quote ‘Nobody should be a prisoner in their own home.’

Local authorities still charge for social care support, and have even increased their charges. They charged for support that was not delivered, and in some cases fined us when we could not pay. This is on top of all the other extra costs and the rising cost-of-living. We are worried that if we cannot pay for this essential support it will be taken away.

Quote 'Paying for support makes things worse.'

There is an ongoing staff shortage and many of us are going without all of the support we need. If our needs are not assessed as being 'critical' or 'substantial' we may get no support at all. Disabled people reported that during lockdown, social workers were working in isolation from each other and communication broke down with a knock-on effect on services.

Disabled people welcomed self-directed support options when the law for this was passed in 2013 because we felt it would give us more choice and control. This is not what happens in reality. Not everyone who could benefit from self-directed support gets it, and it is difficult to navigate the system.

The Scottish Independent Living Fund has the potential to make a difference for thousands of disabled people with complex disabilities but the fund is closed to new applicants. It is estimated that an additional 3500 disabled people could benefit from the fund if it were to open to new applicants.

Quote 'People feel pushed to the brink.'

Solutions – Social Care Support

Bring an urgent end to social care charging – The Scottish Government should take urgent action to cease social care charging, including writing off arrears.

Improve self-directed support – The Scottish Government must improve the implementation of self-directed support across the country so that everyone

can have an assessment, be offered all the options, and make the right choices for themselves.

Open the Scottish Independent Living fund to new applicants – The Scottish Government should open the Independent Living Fund to new applicants as soon as possible.

Health

Quote ‘What happened to early prevention?’

Poverty and the cost-of-living crisis are having a disastrous impact on our health. Our health conditions are worsening and our mental health is suffering because of worries about money, cold and damp, lack of food, increased social isolation and cuts to essential services. There are backlogs in the health service and we are not getting the health care we need for our impairments or ill-health condition. Disabled people are fearful of dying, and people have already died.

Quote ‘I know a good friend who deteriorated before our eyes and died because of this cost-of-living situation.’

Disabled people were also concerned about the progression of assisted dying legislation in Scotland.

Quote ‘Pursuing the Assisted Dying Bill during a cost-of-living crisis is dangerous. Disabled people are already feeling helpless.’

Solutions - Health

More mental health support – The Scottish Government should extend mental health services, ensuring that they are available and accessible for disabled people whenever needed, including preventative mental health support.

Health services – Disabled people’s health needs should be prioritised to prevent new and worsening conditions.

Equipment and digital access

There are few accessible and inclusive opportunities for us to learn how to use digital technology. We need this for learning, employment, keeping informed, shopping, socialising and much more.

Disabled people said they do not learn about the opportunities available to do this and that they do not get the support they need to take up digital training. We might need ongoing support to keep up our skills and knowledge and to build confidence.

Quote ‘Due to the pandemic I lost confidence and had to learn again.’

Disabled people said that broadband affordability coupled with the default position of moving all advice, information and communication online is...

Quote ‘... pushing disabled people into the margins.’

Solutions – Equipment and digital access

Digital inclusion – The Scottish Government, funders and training suppliers should ensure that there is a good

supply across the country of digital inclusion programmes. These should provide kit (including assistive technology), coaching and connectivity, and training opportunities that are fully accessible and inclusive of disabled people.

Housing

Scotland is still a long way from having the housing stock so that we can live in homes that meet our needs. More accessible, affordable housing across all tenures is needed in every region. This housing needs help disabled people withstand the energy crisis now, and in the future as well as other challenges such as flooding due to climate change.

Disabled people spoke about mould and how this makes our health conditions worse.

Quote 'I simply can't get my home above 17 degrees despite being set at 21 degrees because the insulation is so bad'.

Solutions - Housing

Build new – The Scottish Government, working with local authorities, housing associations and private companies must urgently increase the stock of affordable accessible housing. There must be a clear definition of 'affordable'. Disabled tenants should not have to bear the costs of new social housing.

Energy efficient homes – There should be more investment in energy efficiency programmes for housing

which works for all types and tenures of housing. Disabled people's homes should be prioritised for this. Landlords should not pass on costs to tenants via rent increases.

Debt and savings

Disabled people spoke about having to use savings, going into debt and the effect this has on us.

Quote 'If people go into debt their mental health declines.'

We already have fewer savings and our debt costs us a greater part of our income than for non-disabled people^{xi}. This is on top of the extra impairment-related costs disabled people have to pay.

Solutions – Debt and savings

Suspend debts – The collection of public sector debts such as for Social Care Support and Council Tax must be halted. Arrears should be suspended for at least the period of the cost-of-living crisis. The timeframe for writing off council tax debt should be reduced.

Food

One local Disabled People's Organisation (Glasgow Disability Alliance) provides food at their member's events and people have told them it's the first hot meal they have had in weeks.

Disabled people highlighted that food banks can be inaccessible. For those living in rural areas, there are few food banks and little accessible and affordable transport options to go there or to the shops.

Supermarket delivery services do not cover all rural areas forcing people to use expensive local shops. One person welcomed how their local food bank is continuing to do deliveries, something they started during lockdown.

For those who need specialist diets the situation is threatening their health and food banks rarely meet these needs.

Quote ‘I have a special diet for my health condition and the food is very expensive.’

Solutions - Food

Food banks should be accessible and inclusive – Food banks should review their services to ensure that their services are accessible and inclusive and that they support people who need special diets.

Other solutions in this report such as increasing benefits and having ‘cash-first’ approaches can help disabled people access the food they need, including specialist diets.

Getting advice and support

Quote ‘Managing our life is already a full-time job.’

The support we need is hard to find, over-stretched and often inaccessible for disabled people.

Quote 'Being told to go somewhere for help, then it's not available because services like libraries are closing or reducing.'

Quote 'It's too scattered.'

Once we do find the right support, we have to 'negotiate' to get help, even 'beg'.

Disabled people talked about how the advice given is not always right or appropriate for us. Being told to 'wrap up warm' is not a solution for some disabled people.

Volunteers at advice centres that were closed during lockdown have not all returned and their experience and knowledge has been lost.

One disabled person said they asked for mental health support and was given a long list of services to look into. This was overwhelming and they gave up.

Disabled People's Organisations are best placed to support disabled people because we understand what it means to be disabled and about the barriers and complications. Despite this, the cost-of-living crisis is pushing Disabled People's Organisations across the country further into crisis. Premises and heating costs, technology, staff costs, and the costs of meeting access needs are all rising sharply. Organisations are struggling as sources of funding run out or because disabled people are not a priority for funders.

Solutions – Getting advice and support

Fund Disabled People's Organisations and other advice and support providers – National and local government and other funders should stop the cuts to funding for Disabled People's Organisations and put in place adequate and long-term funding.

Advice and support services must be fully accessible and promoted to disabled people – Support and advice services should be accessible and inclusive for disabled people and work with disabled people to build the understanding needed to support us. The Scottish Government should ensure that services that benefit from public funding are required to do this and are monitored to ensure that they do.

Implement the British Sign Language (Scotland) Act 2015 – The implementation of this Act should be reviewed and action taken to ensure everyone meets their duties under this Act, including advice and support services.

Conclusions - Nothing About Us Without Us

This crisis is having a grave and growing impact on our lives and survival.

We were already much more likely to be living in poverty than other people and we are facing this crisis on top of the pandemic and the extra costs of being a disabled person, and years of inequality and exclusion.

Enough is enough. Emergency responses are needed now to protect disabled people's lives.

Too many of the solutions in this report are not new. They should have been in place before now. Urgent action is needed now to break down the deep-rooted structural barriers. Disabled people must never be forgotten when things circumstances change for the worse and decision makers and service providers rush to make emergency changes.

'Politicians need to understand what people are going through. They need to hear us.'

All this must happen with, not to, us disabled people. We are experts by experience in our own lives. We know first hand what happens in reality despite what policies say should happen, and we know best what needs to change.

You can read Inclusion Scotland's current briefing for decision-makers which includes asks made in this report on our website at this page -

<https://inclusionScotland.org/get-informed/our-policy->

focus/poverty-and-social-security. We will keep this briefing up to date and work to ensure that decision-makers hear about and work on these asks, with disabled people.

Nothing about us without us.

Disabled people are stronger together. The time for direct action is now. We must come together as disabled people and Disabled People's Organisations to demand the changes needed.

Mission Statement

Our logo is a blue saltire flag with Inclusion Scotland in orange. Underneath that is Disabled People's Organisation in blue text. Along the bottom is 'Our voices. Our choices'

Inclusion Scotland believes in and is founded upon the social model of disability, we are disabled by the barriers we face rather than our impairments themselves. Using the social model, we work to achieve positive changes to policy and practice, so that all disabled people are fully included throughout all Scottish society as equal citizens.

We do this by:

Influencing decision-makers, ensuring that disabled people are involved in developing effective solutions for policy and practice, that reflect our expertise by experience and meet our needs and aspirations.

Supporting disabled people to be decision-makers themselves, promoting the equal representation of disabled people as policymakers and our right to make decisions about our own lives.

Developing capacity, awareness, and engagement, of disabled people, disabled people's organisations and the organisations and institutions that affect our lives.

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