

Pressure points:

Experiences of the cost-of-living on disabled people and carers in Sussex

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Welcome

Welcome to this report by Independent Lives, developed using Community Participatory Action Research, in collaboration with disabled people and carers.

This report is the culmination of 12 months of work. Over this time, we've had the privilege of meeting some incredible people who have opened their hearts to us, shared their stories and given us insight into the sheer scale of the crisis caused by the rise in the cost-of-living.

Living life as a disabled person or a carer can be incredibly challenging. All three of us have lived experience of disability or caring responsibilities, so not only do we understand those challenges first-hand, but we also understand how important it is to ensure that this report goes beyond words.

We hope its true purpose catalyses tangible, enduring improvements in the lives of those featured, and the countless others across the nation facing similar circumstances.

Finally, a few personal thank yous: to the NHS for giving us this opportunity, to our main research lead, Esther, at the University of Reading, for teaching us the skills we needed to get through to the end of our 'journey'. Lastly, to our mentor Dawn at the Scottish Community Development Centre, for always being incredibly kind and generous with her time and helping us realise when enough research was 'enough'.



Polly Bishop



Cara Redlich



Gareth Shephard

Independent Lives' community researchers

Foreword

I am incredibly proud that Independent Lives has had the opportunity to be involved in such valuable and vital research.

In this report, Independent Lives aims to represent the perspectives of disabled people and carers in Sussex. In 2022, we conducted a comprehensive study to understand the challenges faced by our members, the Friends of Independent Lives. The study revealed that the cost-of-living was a significant concern.

Formed by disabled people more than twenty years ago, it is inspiring to witness the development and fruition of a project like this, which truly values and amplifies every single voice. Our commitment to inclusivity and representation remains as strong as ever.

In 2023, Independent Lives received funding from the NHS to conduct a Community Participatory Action Research study in collaboration with the University of Reading and the Scottish Community Development Centre.

The experiences, views, and heartfelt pleas expressed by participants in this research bring to light the stark realities faced by disabled people and carers every day. For those with lived experience, much of what you read may resonate deeply. We hope this report will provide valuable insights into the severe impact of the cost-of-living crisis on disabled people and carers, fostering greater understanding and empathy among all readers.

Disabled people and carers are being forced to make significant lifestyle changes, yet they continue to struggle. Our research found that 42% of people surveyed have been affected by rising heating costs, and 36% are skipping meals or adjusting their food intake to make ends meet.

The cost-of-living crisis exacerbates existing challenges, such as inadequate financial support, limited access to essential services, and social isolation. More must be done to support people so that they may thrive and not just survive. This includes advocating for increased financial assistance, ensuring better access to healthcare and support services, and strengthening community networks to provide a robust support system.

I would like to express my deepest gratitude to our team of dedicated community researchers and everyone who has supported or contributed to this project. Your hard work, openness, and compassion is truly inspiring. Your contributions are invaluable, and I believe they will play a significant role in shaping a better future for disabled people and carers across the UK.

The impact of your work extends beyond this report. It serves as a call to action for policymakers, service providers, and the broader community. We must all come together to address these pressing issues and create an environment where disabled people and carers are valued, supported, and empowered.

Let us use this research as a foundation to advocate for meaningful change and build a society that is inclusive and equitable for everyone, where people are able to thrive and not just survive.



Rebecca Smicle

Independent Lives CEO



Executive summary

Our report reveals the severe impact of the cost-of-living crisis on disabled people and carers.

Key findings

Heating, eating, or care: 42% of participants reported difficulties in affording heating, and 36% have changed their eating habits. Many must choose between essential needs, leading to significant health risks.

Mental health: Financial stress and social isolation have worsened mental health issues. 80% of participants reported an impact on their mental health due to financial constraints.

Feeling trapped: Many disabled people and carers feel trapped by financial limitations, preventing them from taking part in everyday activities and worsening their quality of life.

Surviving, not thriving: Most participants say they are merely surviving, unable to invest in their health and happiness due to financial strain.

Key recommendations

Benefits support: Provide more financial assistance, such as increasing DLA, PIP, and Carer's Allowance, as well as additional cost-of-living payments or adjustments to existing benefits.

Living expenses: Increase assistance with daily living expenses, such as reduced rates for utilities, help with heating, dietary support, and transportation.

Health and social care: Fund more affordable health services and better social care. Cap care contributions, prioritise rehabilitation and family services, and give more weight to doctors' opinions in the healthcare system.

Discounts and concessions: Participants suggest various forms of discounts on things like public transport, social activities (cinema, eating out), and necessary services like MOT costs.

Improved access: Create more user-friendly and efficient access to services, stop benefit cuts, and simplify the application process for benefits which many people find difficult and stressful.

Conclusion

The findings of this report underscore the urgent need for targeted interventions to support disabled people and carers. By addressing these issues, we can help them not only survive but thrive.

We call on policymakers, service providers, and the broader community to take immediate action to address these challenges and build a more inclusive and fair society.

Find out more

You can read the full cost-of-living survey on the Independent Lives website. This includes all survey responses and a selection of videos. Please visit

www.independentlives.org/CPAR-research-findings
to read more.



Independent Lives' cost-of-living steering group

To ensure that the voices of disabled people and carers were central to our research, we set up a dedicated steering group.

This group was formed to guide and shape the project's direction, ensuring it remained true to the lived experiences and insights of those most affected by the cost-of-living crisis.

We began recruiting members for the steering group on 4 August 2023, through a comprehensive outreach campaign that included our website, social media channels, and e-newsletters.

The steering group had five members, all with lived experience of disability or caring responsibilities. They provided invaluable perspectives for our research. From September 2023 to May 2024, we held four meetings with them.

Members offered crucial feedback on various aspects of the project, ranging from the design of survey questions to the review of the final report. Their contributions were essential in ensuring that our research accurately represents the challenges faced by disabled people and carers.

By working with those directly affected by the issues we have studied, we've tried our best to make sure that our research is not only relevant but also driven by our community's needs and perspectives.

The steering group played a key role in Community Participatory Action Research, putting the community at the center of our project. Their

involvement has shaped our project to truly reflect their lived experiences, making our findings stronger and more actionable.

We're so thankful to the steering group members for their dedication and contributions, which have been essential to the success of our project. Their input has made sure that our research isn't just about our community but is conducted with and for our community.

We want to express our sincere gratitude to each member for their time, effort, and invaluable insights. Their contributions have been crucial in creating a project that accurately represents our community's needs and aspirations.

“ It is vitally important to emphasise how the most vulnerable in society have been affected by the cost-of-living crisis.

Too often, the daily challenges faced by people with disabilities go unnoticed by many others. Likewise, carers are a very silent army who save the NHS and social services millions of pounds each year.

As a former full-time carer, I understand only too well how lonely and isolating the experience can be, before even beginning to touch on the subject of financial constraints - Carer's Allowance is the lowest paid social security benefit.

It has been a privilege to be part of the steering group researching this crucial, yet often overlooked issue and I would like to thank everyone at Independent Lives for all their efforts. Some of the discoveries have been shocking, though regrettably, unsurprising.

- **Jonathan, steering group member**

Survey analysis and data

We began collecting data by running a survey to ask for information from disabled people and carers across Sussex. Here's what we found.

We conducted our survey over a period of nearly four weeks, from Monday, 13 November, to Friday, 8 December. During this time, we received 138 responses, although not every person answered every question.

The survey was designed to cover a wide range of experiences, with the aim of obtaining a comprehensive understanding of the impact of the cost-of-living crisis on disabled individuals and carers across Sussex.

The data collected, which includes both qualitative and quantitative responses, provides a detailed and nuanced insight into the experiences of the participants.

Analysis and implications

The survey results illustrate the significant impact of the cost-of-living crisis on disabled people and carers in Sussex. The data we've collected shows that the vast majority are facing considerable hardships due to increasing living costs.

Broad impact and hardship

With **95.08% (116 out of 122)** of participants confirming that they are affected by the cost-of-living crisis, financial strain is nearly universal among the people we surveyed. This widespread impact emphasises the urgent need for targeted interventions to support them.

Health and well-being deterioration

The cost-of-living crisis is not just a financial issue; it has far-reaching implications for physical and mental health, quality of life, and daily activities:

Physical health: 64.47% (78 out of 121) reported negative impacts on their physical health, indicating that the inability to afford necessities such as adequate heating and nutritious food is taking a toll.

Mental health: 81.81% (99 out of 121) indicated a negative impact on their mental health. This statistic highlights the mental toll of constant financial stress, which can exacerbate existing mental health conditions and contribute to new ones.

Quality of life: 78.51% (95 out of 121) reported a decline in their overall quality of life, suggesting that financial constraints significantly limit their ability to engage in enjoyable or meaningful activities.

Daily activities: 76.47% (91 out of 119) stated that their daily activities are negatively affected, reflecting the impact of financial hardship on routine and independence.

Lifestyle adjustments and coping strategies

90.16% (110 out of 122) have had to adjust their budgeting or lifestyle due to the increased cost-of-living. This statistic demonstrates the adaptability and resilience of disabled people and carers but also highlights the severe sacrifices they are having to make. These changes often involve reducing spending on essential items, which can have further negative implications.

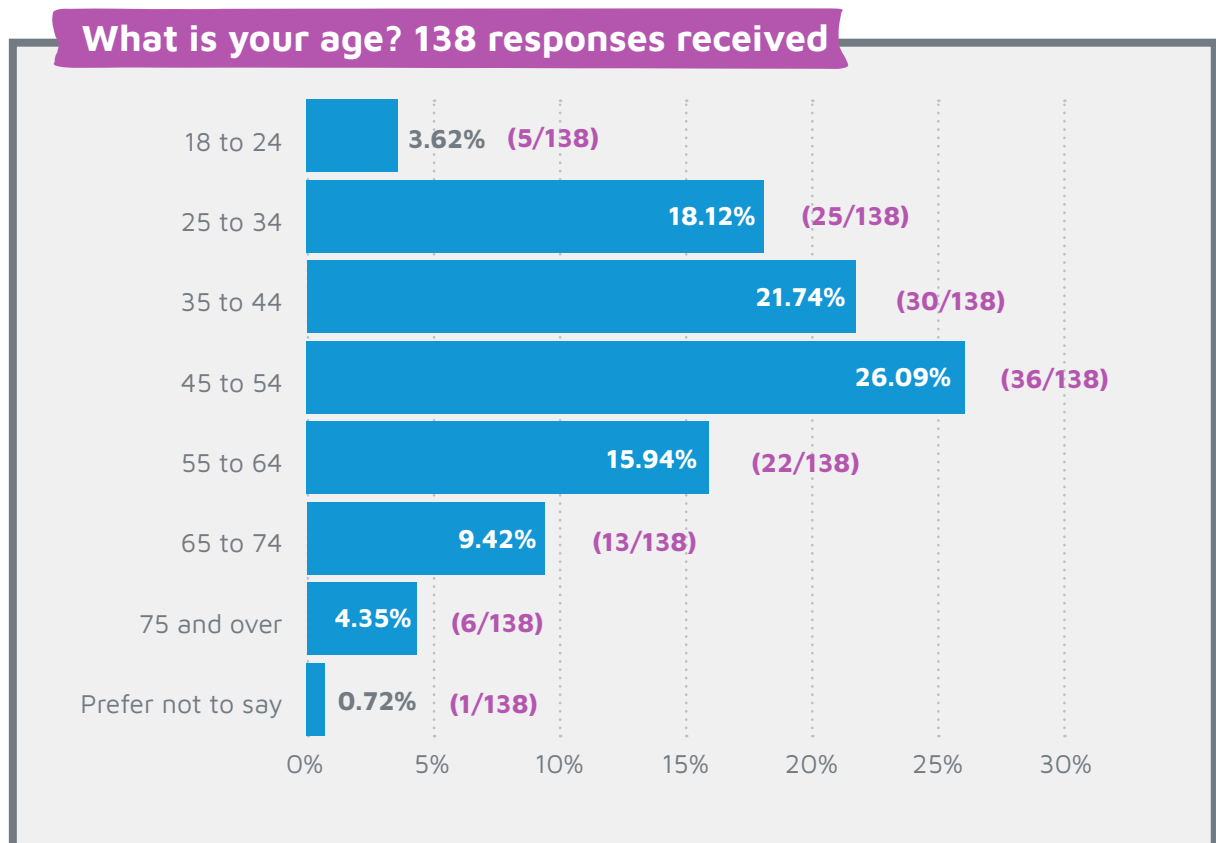
Impact on NHS services

56.20% (68 out of 121) felt that the cost-of-living crisis has affected the level and quality of care they receive from the NHS. Feedback suggests that financial pressures are leading to longer wait times, reduced access to services, and potentially lower quality of care, all of which compound the difficulties faced by disabled individuals and carers.

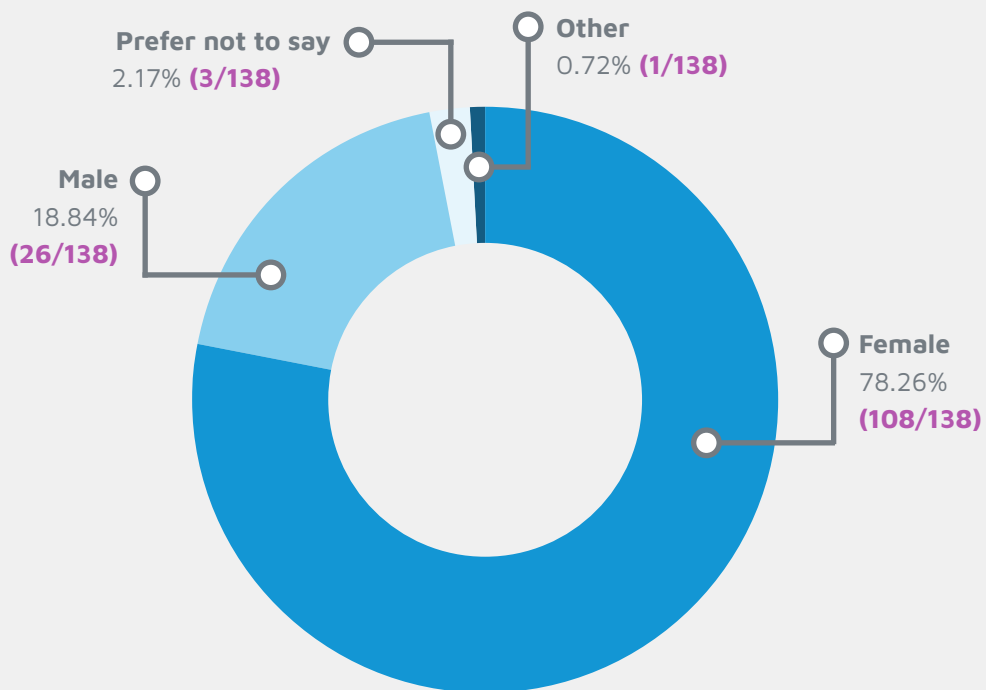
Heightened vulnerability

80.17% (97 of 121) of disabled individuals and carers felt more affected by the cost-of-living crisis compared to the general population. This heightened vulnerability points to the need for specific, tailored support measures that address their unique challenges.

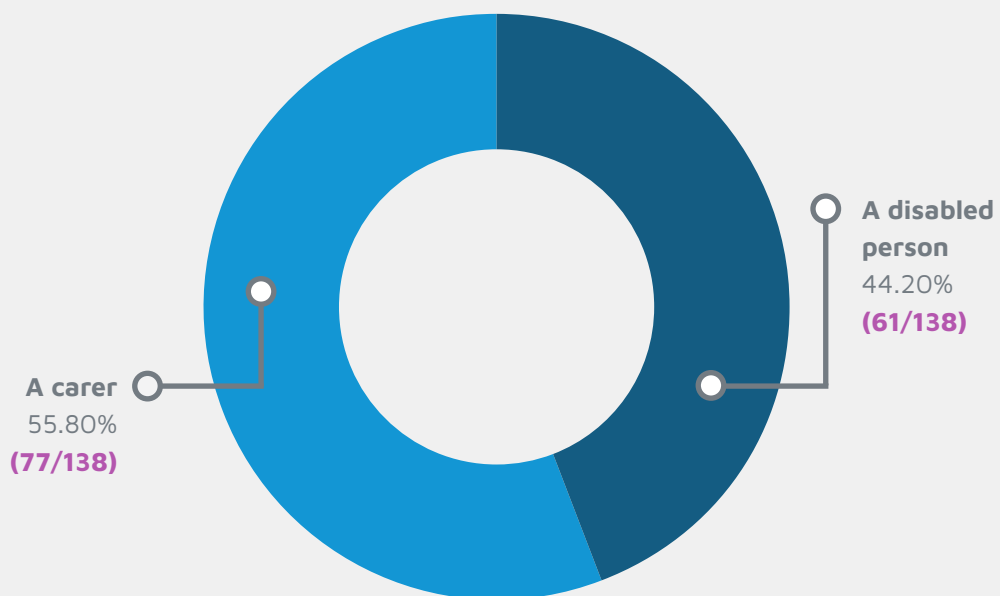
Survey data: demographics



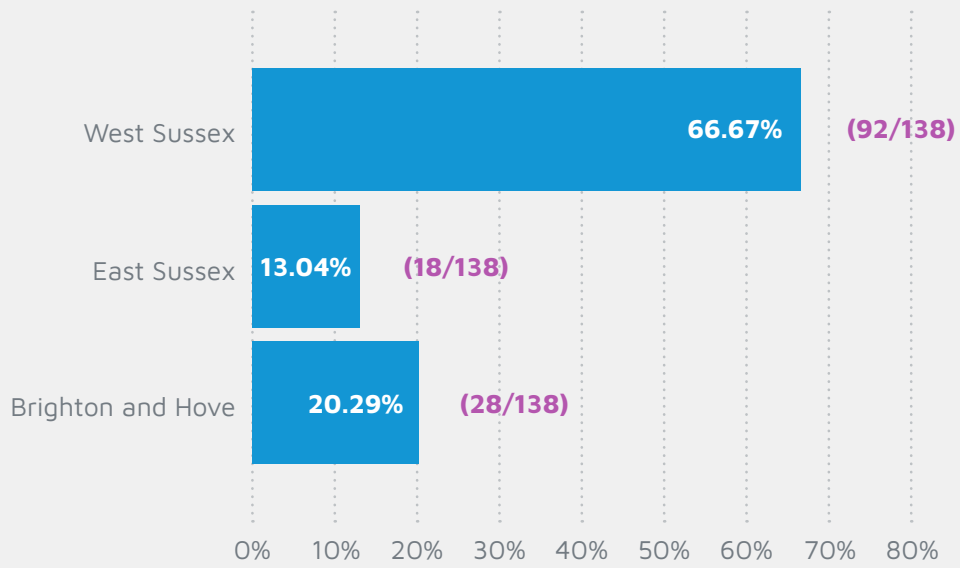
What is your gender? 138 responses received



Are you answering as... 138 responses received

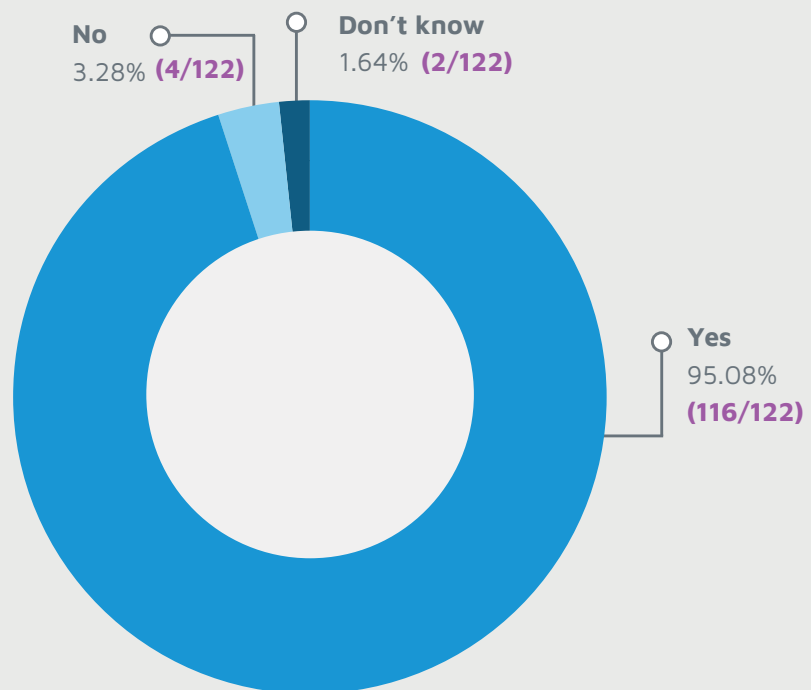


Which area do you live in? 138 responses received

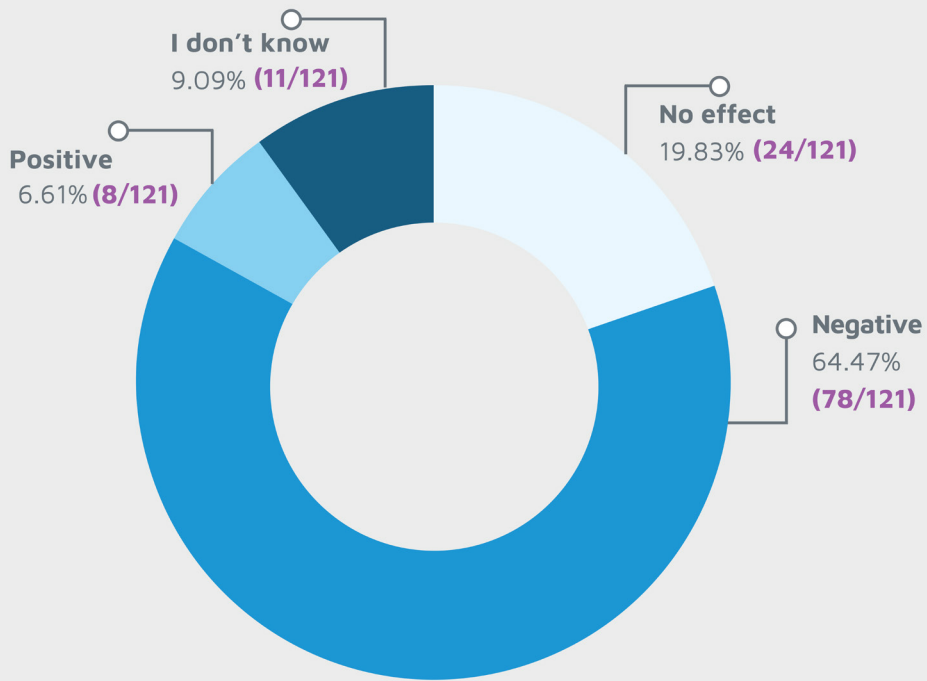


Survey data: Cost-of-living

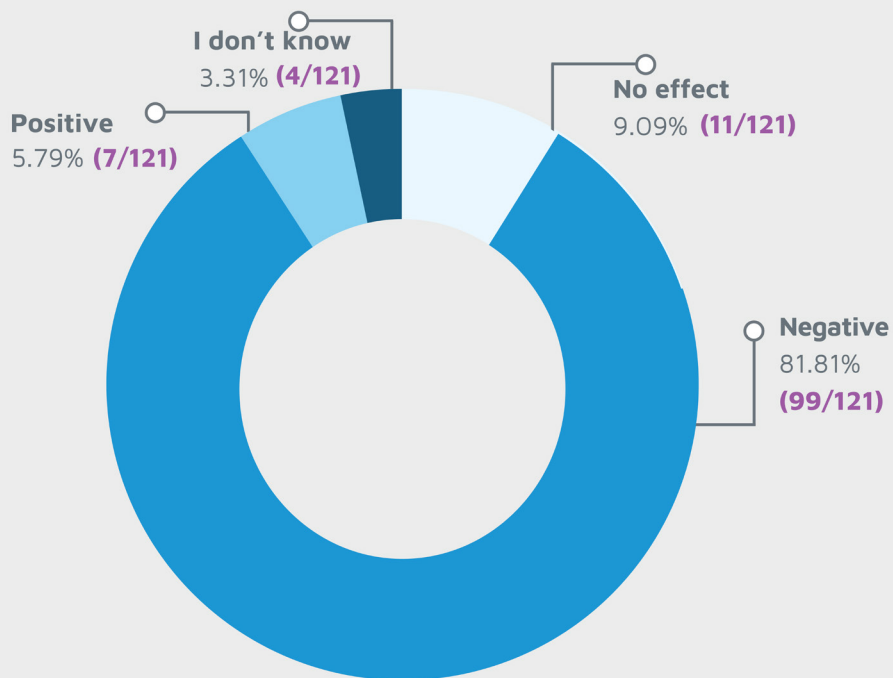
Are you affected by the cost-of-living? 122 responses received



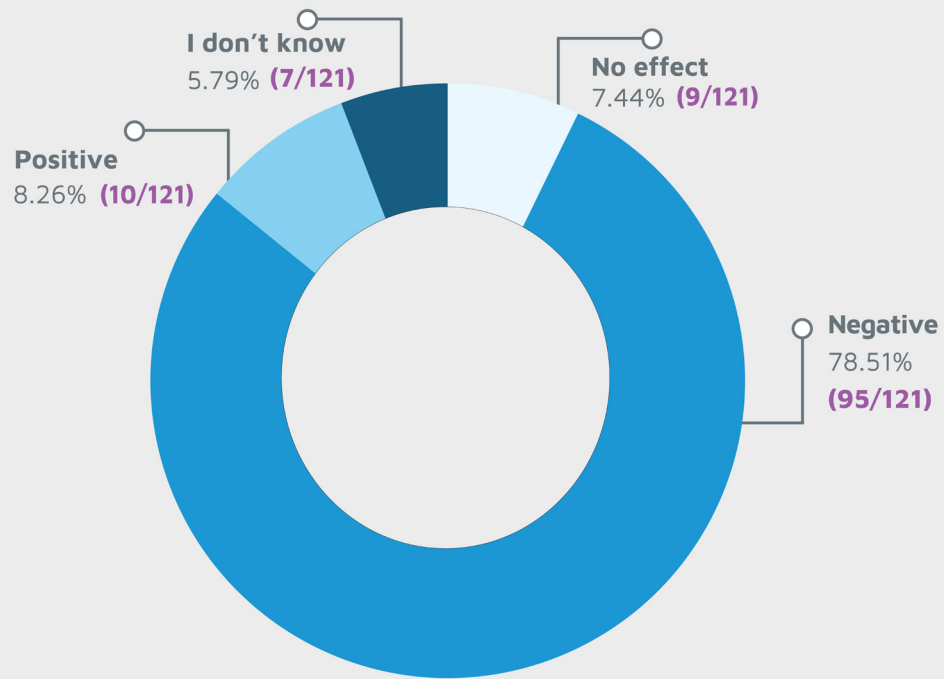
Please rate the effect the cost-of-living has had on your physical health. 121 responses



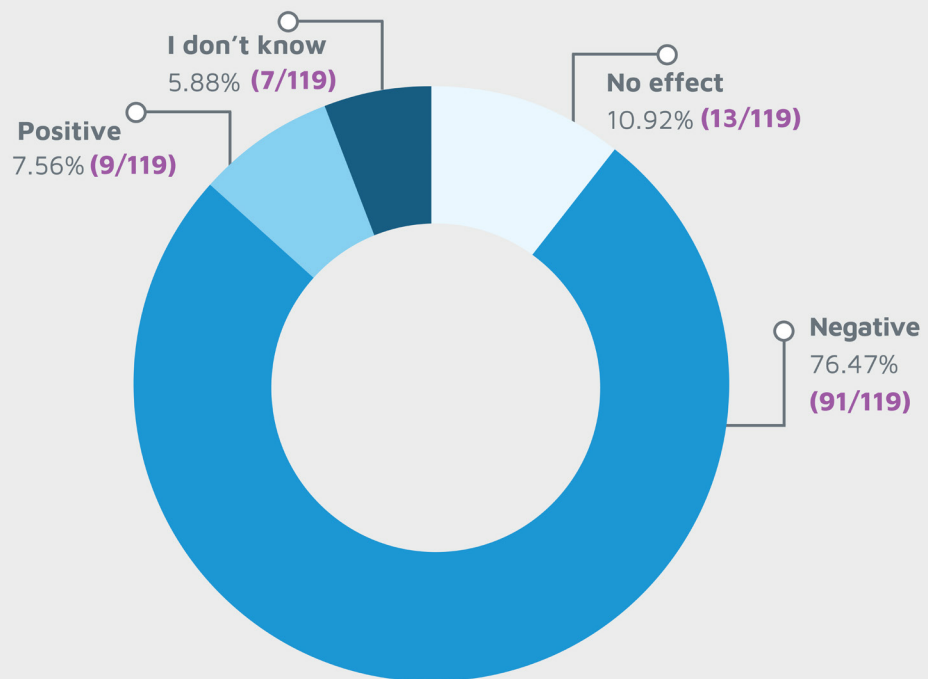
Please rate the effect the cost-of-living has had on your mental health. 121 responses



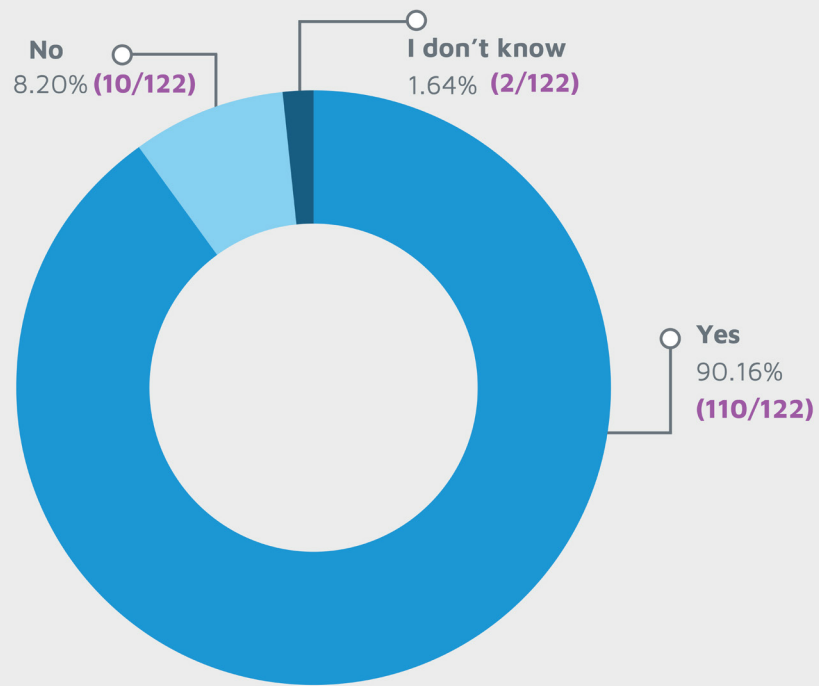
Please rate the effect the cost-of-living has had on your quality of life. 121 responses



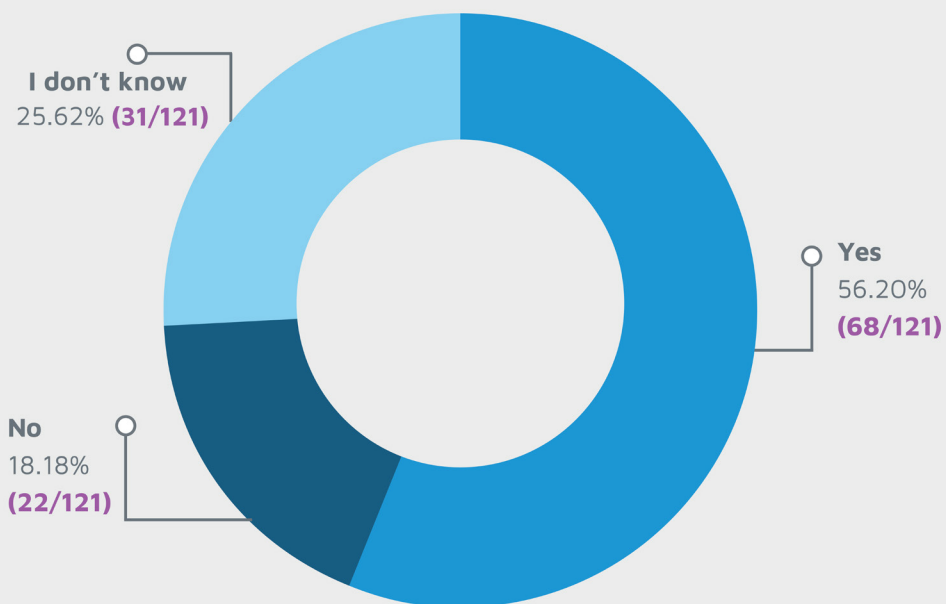
Please rate the effect the cost-of-living has had on your daily activities. 119 responses



Have you had to make any changes to your budgeting or lifestyle due to the cost-of-living? 122 responses



Do you feel the cost-of-living has had an effect on the level and quality of care you receive from the NHS? 121 responses





138 disabled people and carers from across Sussex took part in our survey.

Gemma, Archie's mum.

Key findings

Our research reveals a community struggling to cope with the increased cost-of-living, where disabled individuals and carers face stark choices about their most basic needs.

The cumulative effect of these financial pressures is a significant deterioration in quality of life, encompassing physical health, mental well-being, and overall life satisfaction. The responses highlight the severe implications of economic hardship and call for urgent and targeted interventions to support two of society's most vulnerable groups

Heating, eating or care

Survey responses underscore the harsh trade-offs between essential needs. A substantial number of participants must choose daily between adequate heating, proper nutrition, or sufficient care services, as financial resources do not stretch to cover all necessities.

Feeling trapped

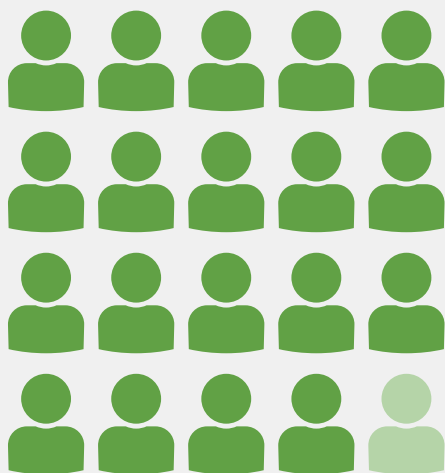
Many participants express a sense of entrapment, constrained by financial limitations that prevent them from engaging in previously normal activities. The crisis has led to a dramatic reduction in their mobility and social interaction, contributing to a life that feels smaller and more confined.

Mental health

The survey data clearly indicates that the cost-of-living crisis is taking a significant toll on mental health, with many participants reporting increased anxiety, depression, and isolation. The constant stress of managing on a tight budget, as well as the reduction in social contact and activities, exacerbates existing mental health conditions and contributes to new ones.

Surviving, not thriving

Participants frequently mention just barely surviving rather than thriving, with financial constraints stripping them of the ability to enjoy life or invest in their health and happiness. The general theme is one of constant struggle to cover basic living costs, with no room for leisure, self-care, or unplanned expenses.



95%

of our survey participants told us that they had been affected by the cost-of-living crisis.

Heating, eating or care

The cost-of-living crisis has placed a disproportionately heavy burden on disabled people and carers, forcing them into a critical and distressing decision-making process over their most basic needs: heating, eating, and care.

This group faces a big challenge because their basic needs — heating, eating, and care — are essential for their health and well-being, not just for comfort. Making tough choices between these needs can have serious effects on their health, happiness, and overall quality of life.

For instance, heating is crucial not just for warmth but also for managing health issues that get worse in the cold, like muscle stiffness and pain from conditions such as multiple sclerosis or severe arthritis. Also, having the right diet is vital for managing health conditions, so reducing food costs is more than just saving money—it could risk their health.

“ A non-disabled person might be able to survive winter without heating, albeit with some discomfort, but I literally can't breathe



90%

of our survey respondents told us that they had to make **changes to their budgeting or lifestyle** due to the cost-of-living.

without the heating on and I spend my nights buried under a pile of blankets and duvets and just trying to catch a decent breath.

Additionally, the need for professional care services, which are important for daily life and independence, often clashes with other essential needs because of limited budgets.

“ I feel like the cost-of-living has put a strain on the NHS, leading to longer waiting times, fewer resources, and increased stress for staff. This can impact the quality of care that patients receive.

These critical needs put disabled people and carers in constant crisis mode, where missing one essential can hurt access to or the quality of the others. This ongoing struggle is made even harder by the overall increase in costs.



GP concerns over rise in signs of malnutrition

Much of our research seems to back up what has already been reported by doctors working in some of the most deprived areas¹. However, our research indicates these effects may be experienced in less deprived areas.

In 2023, the BBC reported that GP's in Scotland were concerned about malnutrition caused by the cost-of-living crisis.

The article reports that people were being forced to choose less nutritious foods with wide ranging health implications.

¹ <https://www.bbc.co.uk/news/uk-scotland-64518568>

Comment

- 1 Everything has gone up. Gas, electric, rent, food, public transport to get to hospital appointments. Meaning difficulties in choosing priorities. I often eat less than the children and prioritise their appointments and needs.
- 2 [We are] struggling every month once rent is paid and bills, [we are] left with £60 to do food shopping. Worrying about bills constantly. Worrying about my child's needs constantly. Needing to borrow money but then struggles to pay back.
- 3 I've had to reduce my hours at work to care for my child and it's only thanks to help from family that we've been okay.
- 4 Unable to afford to put the electric heater on. Rented accommodation has no central heating, only night storage heaters which do not work. I get a lot more pain in my joints from feeling so cold.
- 5 Extra cost on bills, son is incontinent so lots of washing, electric bill is high. He requires extra washing to keep clean, gas bill high for hot water.
- 6 Everything is more expensive. When caring for a disabled person who has special dietary needs... we have had to cut back on a lot of things.
- 7 Sometimes my children will eat and I would eat toast or leftovers.
- 8 A lot of times, we forgo meals in-between. We sacrifice a lot of comfort to afford medical care. We live in an uncomfortable home.
- 9 I've had to miss important appointments because of means not being there for me or the children. I also have gone plenty a day without a meal so the children are well fed. Same with clothes.
- 10 I no longer see an osteopath and chiropractor for my disability as we cannot afford it... I take on extra work at the weekends to try and get some money in so I feel that I am not spending much time with the children either.



I also have gone plenty a day without a meal so the children are well fed.

Feeling trapped

The theme of “feeling trapped” emerges powerfully in the narratives of disabled individuals and carers grappling with the cost-of-living crisis.

This feeling highlights the tough reality of living with restrictions that greatly limit personal freedom and the ability to make everyday choices that others often take for granted. For many in this group, rising costs for basic needs like food, heating, and care services create a deep sense of being trapped, both physically and mentally.

The sense of being stuck with limited options is prevalent in our research with one survey respondent telling us:

“ I am unable to find a better job as to do so I need a car, and I can't afford to get a driving licence or a car, so I am trapped working part time locally.

Another told us:

“ I am miserable because I feel trapped and lacking options to get ahead.

The crisis creates a harmful cycle: financial stress causes people to withdraw socially and physically, which worsens health problems and increases loneliness. This feeling of being trapped not only reduces the quality of life right now but also affects long-term well-being, making it harder to see any way out of the situation.

For many, the cost-of-living crisis isn't just a temporary problem but a major disruption that turns life into a struggle for survival instead

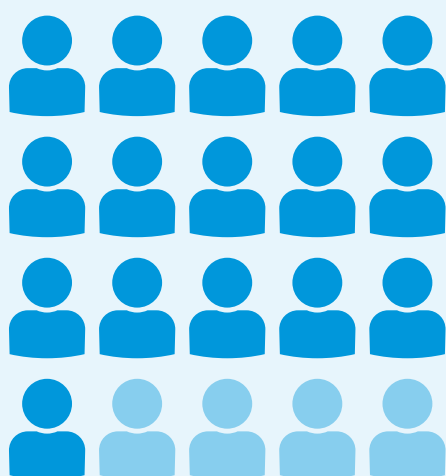
of truly living. This feeling of being stuck shows the critical need for focused support and action to break these cycles of difficulty and give back a sense of control and hope to those most impacted.

The sense of being trapped extends beyond personal finances to a broader sense of systemic failure. One respondent explained:

“ The government keeps telling us that ‘working is the way out of poverty,’ but as a public sector worker the same government also sets my wages and they are too low for a non-disabled person to live, never mind a disabled person.

This widespread sense of entrapment underscores the urgent need for policies and interventions that address not only the financial strain but also the associated emotional and psychological toll.

Enhancing social support systems, improving access to mental health resources, and ensuring adequate financial aid are critical steps towards alleviating the feeling of being trapped.



80%

of our survey participants told us that being a disabled person or carer had **increased the effect** of the cost-of-living on them.

Comment

1 I feel very scared and the fear is always there. I read articles in newspapers about how the government wants to reduce my benefits, and this is scary.

2 My son was given a maximum of two years to live. My husband needed to deal with this news but had to go back to work.

3 My illness has increased in severity as I cannot afford the disability-related expenses that are necessary. I don't have family or friends to rely on, only my carers.

4 I've had to cut out everything that makes this terrible existence tolerable... I don't have TV or a computer to keep myself occupied.. I don't have any friends anymore either.

5 I am miserable because I feel trapped and lacking options to get ahead. I have to be so careful using as little electricity as I can. It's absolutely miserable and all the work feels pointless.

6 Both my husband and I are disabled, we don't go out unless we really have to.

7 It's expensive to stay at home due to electricity and gas and food costs. And it's expensive to go out. I spend a lot of time looking for coupons just to get out.

8 My contribution towards care is my highest single outgoing and I don't have any choice, it used to cover 20 hours per week... now the same budget only pays for seven hours.

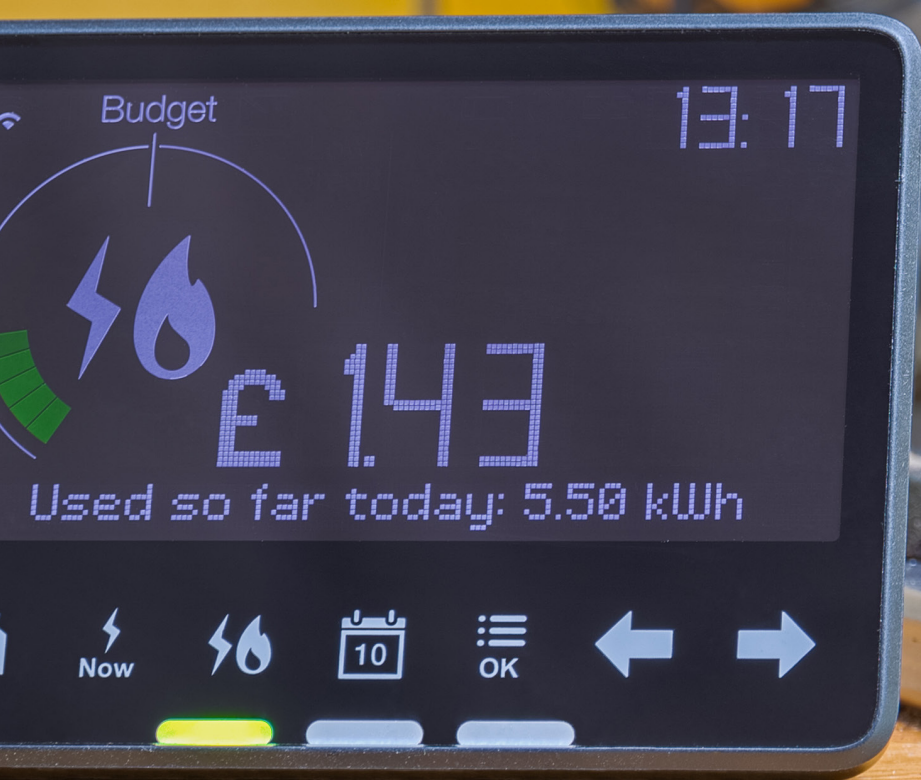
9 It's all about money. We don't have confidence that the NHS is there for us anymore. Pensioners and disabled [people] are at the bottom of the pile.

10 The cost of things are higher because of my daughter's disability. Our daughter requires more expensive foods due to her conditions. We use far more electricity due to medical equipment in the home.

11 As a carer I can't go and earn more money. I need to be with my husband 24/7.



Everything costs more as a disabled person and so with everything going up due to cost-of-living I'm even more stuck.



Mental health

The mental health impacts of the cost-of-living crisis on disabled individuals and carers are profound and multifaceted, deeply entwined with the escalating financial pressures that many face.

This crisis has not only intensified existing mental health issues but also precipitated new ones, creating a pervasive atmosphere of stress, anxiety, and uncertainty that deeply affects this vulnerable population.

Financial stress is a significant contributor to mental health deterioration. The constant worry over how to allocate limited resources—choosing between heating, eating, or essential care—can lead to chronic stress and anxiety. This financial strain is not merely about managing budgets but is a daily confrontation with critical decisions that affect health and survival.

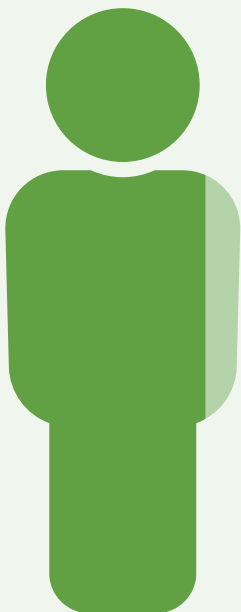
“ I am more worried about money, I am going out less, I am not able to afford the usual things I use for self-care for my mental health, and I am in pain because I am cold.

Social isolation further exacerbates mental health challenges. The reduction in social interactions, whether due to physical limitations, financial constraints, or both, leads to a sense of isolation and loneliness. Activities that were once sources of joy and connection—such as meeting friends, participating in community events, or simply going out for a meal—become luxuries that many can no longer afford. This loss of social engagement deprives individuals of essential support networks, increasing feelings of isolation and contributing to depressive symptoms.

“ The rising cost-of-living has made it difficult to enjoy life. I have had to cut back on activities that I enjoy, such as going out to eat and seeing friends. I also feel like I am constantly on edge, waiting for the next bill to come in. This has made it difficult to relax and enjoy the present moment.

Moreover, the relentless nature of these stressors—with no clear end in sight—can lead to a sense of hopelessness and despair, impacting individuals’ outlook on life and overall well-being. The cumulative effect of these stressors can be severe, leading to increased incidences of anxiety disorders, depression, and in extreme cases, suicidal ideation.

“ We’ve all suffered with mental health needing help from GP and well-being, medication, two of us felt suicidal feelings at different times, too much stress, can’t afford to go into town or travel or socialise sometimes etc.



82%

of our survey participants told us that their **mental health** had been negatively affected by the cost-of-living crisis.

Comment

1 Hearing what other people are still doing and enjoying negatively impacts my mental health as I would like to do simple things like go to the cinema once in a while but my first thought is always, always, how much will it cost? Can I afford it?

2 [I] can no longer go to the gym which has impacted on my mental health and quality of life.

3 The fear never goes away. I have always been anxious and it feels like things are going to get worse.

4 The rising cost-of-living has caused me a great deal of anxiety and depression. I worry constantly about money and my ability to make ends meet. I also feel guilty about not being able to provide more for my family.

5 As a person with a disability, I have found that the rising cost-of-living has had a significant impact on my life. I have additional expenses related to my disability, such as the cost of medication, assistive technology, and transportation. I am also more likely to have a lower income than non-disabled people, making it harder to make ends meet. This has made it difficult for me to afford basic necessities, such as food and energy. I have also had to cut back on activities that I enjoy, such as going out to eat and seeing friends. This has made me feel isolated and lonely.

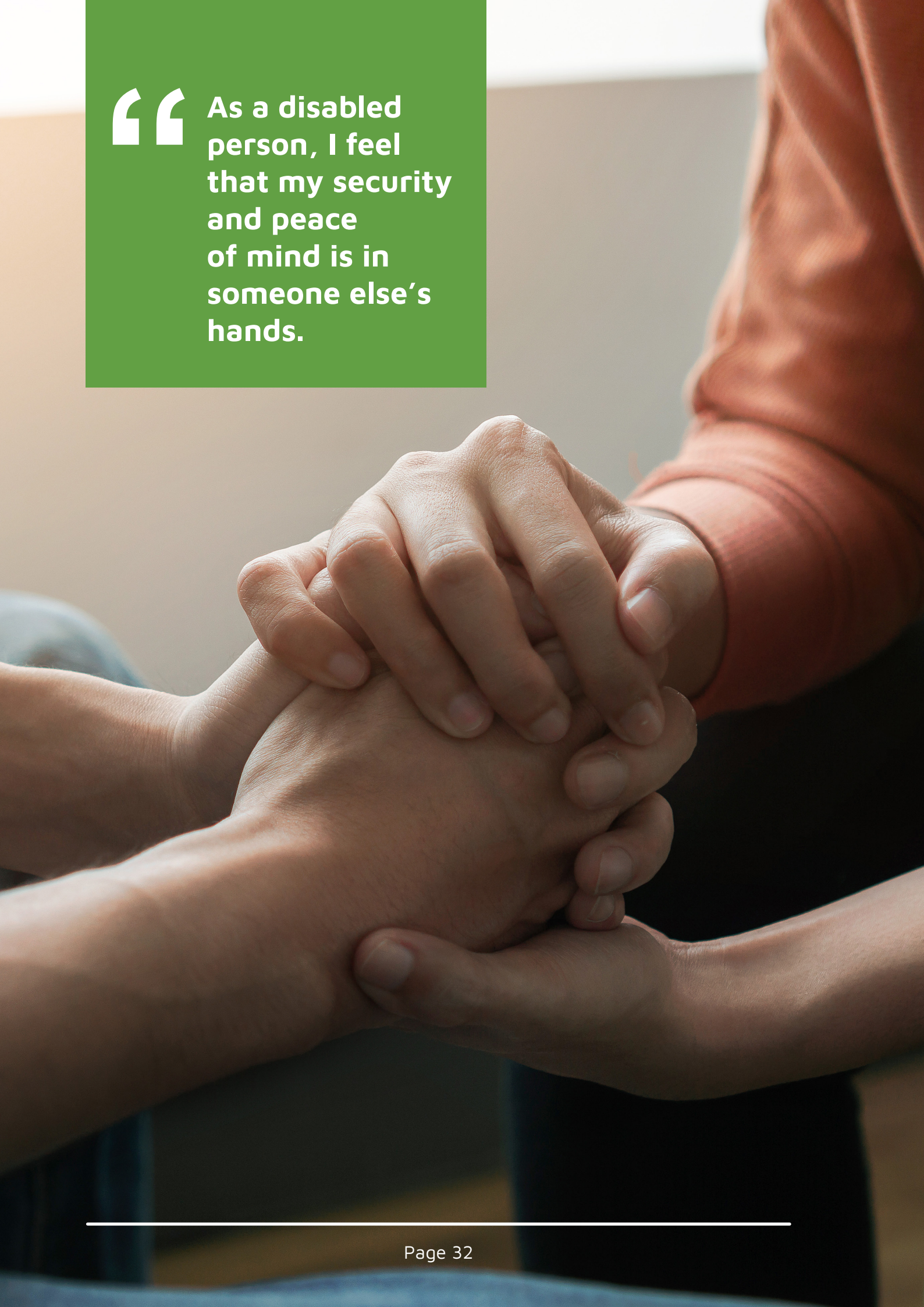
6 I need therapy to help with my mental health and this is only available privately.

7 I think that because we are on a fixed income we cannot improve our circumstance. My husband is my full time carer. As a disabled person, I feel that my security and peace of mind is in someone else's hands.

8 The government is talking about reducing benefits for sick and disabled people. This causes huge anxiety for us as a family as our daughter cannot read or understand money and is incredibly vulnerable. She needs her disability benefits to survive.



As a disabled person, I feel that my security and peace of mind is in someone else's hands.



Surviving, not thriving

Our research subjects frequently find themselves in survival mode, constantly battling to meet basic needs while their aspirations for a fulfilling and active life recede into the background.

The perpetual state of just getting by is a profound testament to the severe impact of financial strain exacerbated by rising costs and inadequate support systems.

Survival mode for many involves making painful choices daily. Essential aspects of living such as nutritious meals, adequate heating, and necessary healthcare are frequently compromised. Many are forced to prioritise one essential over another, often at the cost of their health and wellbeing.

“ A non-disabled person might be able to survive a winter without heating, albeit with some discomfort, but I literally can't breathe without the heating on, and I spend my nights buried under a pile of blankets and duvets and just trying to catch a decent breath.

Opportunities for personal development, social interaction, and recreational activities that



78%

of our survey respondents told us that their **quality of life** had been negatively affected by the cost-of-living crisis.

enhance quality of life are often deemed luxuries. The financial barriers to accessing these resources mean that many disabled people and carers live in a state of isolation and monotony, which severely impacts their mental health and diminishes their life satisfaction.

“ ... without the stimulation of going out and about as much, my family member becomes more isolated from social experiences which he needs to have, we all do, but because he is autistic, he needs interactions on his level so he can keep up his limited communication else he will lose it.

The financial strain has a cascading effect, forcing individuals into a relentless struggle to make ends meet. One respondent shared:

“ It is hard to enjoy life when life is currently only about working enough to stay off the streets.

This quote underscores the harsh reality that for many, life has become a relentless struggle to secure basic necessities, leaving little room for joy or personal fulfillment. The constant pressure to work merely to avoid homelessness strips individuals of the ability to invest in their well-being and happiness. Instead of thriving, they are caught in a survival loop, where the focus is solely on meeting immediate needs rather than pursuing long-term goals or personal growth.

Addressing this crisis requires more than temporary relief; it necessitates structural changes to ensure that disabled individuals and carers are not just surviving but have the resources and support to thrive. Such changes involve enhancing social safety nets, ensuring adequate healthcare, and fostering inclusive communities that recognise and address the unique challenges faced by this vulnerable population.

	Comment
1	The cost of bills has increased. We are having to sell our house to meet costs the of supporting our daughter who has ADHD.
2	My son's 1:1 carer had to resign his job as a very effective and skilled carer to work at a large retail shop as he was not getting paid enough to get by. This has had a direct impact on my son's ability to access the curriculum and has put the rest of the school staff under huge pressure.
3	I worry about money all the time, this then causes me physical problems like headaches and fatigue. I used to enjoy days out with my daughter like going to the swimming pool or cinema, I can no longer afford to do these things.
4	My child is constantly worrying about money and doesn't want to ask for basic things that are needed.
5	Forget heating, it doesn't happen. And I definitely can't afford three meals a day either.
6	I eat one meal at most 4/5 days a week so my children can eat. I'm unable to put the heating on due to the debt I'm in. I'm unable to travel to a food bank due to not having money for buses.
7	I go to visit my elderly mum in her care home less because it costs so much fuel to get there. She gives me 'diesel money' so we can visit and I'm 53.
8	It all seems very short-sighted financially and being the person who has to live through it is maddening and heartbreaking. I just want to be given a chance at being well and independent, why is that too much to ask?
9	I feel like disabled people have been forgotten [without] any extra help offered... my daughter also has lots of equipment needing power and no consideration or help offered in the cost of keeping these things running.

“

I just want to be given a chance at being well and independent, why is that too much to ask?



Gemma and Archie's story

We held eight face-to-face interviews with disabled people and carers to find out how the cost-of-living crisis has affected them.

Gemma is the full-time carer for her 12-year-old son, Archie, who has Pompe disease, a genetic disorder which impairs muscle and respiratory function, requiring round-the-clock care. She lives in West Sussex with Archie, her husband, and her daughter.

Archie was diagnosed with Pompe at four months old. Gemma and her husband were told that he would likely not make it to his first birthday. Experts at Great Ormond Street advised that a new treatment was available but that it may not work.

“ We decided to go ahead with it. We said, ‘he deserves a chance, so let’s go for it’. And he bossed it, he got through it really well. He was only little, but he got through it:

Because of Archie’s complex needs, Gemma eventually gave up work as an English teacher to look after him full-time, which negatively impacted the family’s income. During the Covid pandemic, Gemma’s husband had to stay off work to protect Archie. When restrictions lessened, he was only offered one day of work a week, forcing him to become self-employed:

“ Being self-employed means that when [my husband] is not well - so he could have three days off sick one week - that means obviously we’re not going to get... we’ve lost that money. So the following week, we’re without that money. And then we’re always playing catch up.

Then, the cost-of-living crisis hit.

“ I’ve almost doubled what I spend in a week on food because everything costs so much more - also, we have Archie. Archie is completely reliant on electricity. He wouldn’t be alive without electricity. We don’t have any option other than to use electricity in our home. We can’t budget that. It’s got to be constant.

For Gemma and Archie, like many other people in their position, the impact of the cost-of-living on their lives goes beyond the financial and has a profound effect on the level of support they receive from the NHS:

“ Since Brexit, getting certain medications and things like that is an absolute nightmare. Pharmacies are now struggling because the government is only paying them two-thirds of the cost of medication... I get fobbed off by pharmacies all the time: ‘We can’t get it.’ That’s what they tell me: ‘We can’t get it.’ It’s all to do with money. Everything has to do with money.

All of this, coupled with being the full-time carer for Archie for over a decade, has left Gemma struggling to cope:

“ The fact that I’m sitting there having to watch my son die, and I don’t know when it’s going to be, is killing me. That teamed up with the stresses of everything else, I had to admit to my husband - and this has just happened recently - that life has broken me. I am broken, and struggling to do this on my own.

Cost-of-living and the NHS

The cost-of-living crisis has significantly affected the quality of care that disabled people and carers receive from the NHS.

This section covers the challenges and deteriorations in service as reported by participants, highlighting the critical need for systemic support and intervention.

One of the most common issues reported is the significant increase in waiting times for both GP appointments and specialist referrals. Many participants mentioned difficulties in securing timely appointments, with some waiting months or even years for necessary medical consultations and treatments. This delay in care not only exacerbates existing health conditions but also heightens anxiety and mental health issues among patients.

“ I’m waiting for results for a brain scan, body scan, lung function test—it’s been nearly five months. This is impacting my mental health.

The NHS is experiencing severe staffing shortages, exacerbated by the rising cost-of-living, which makes it difficult for many healthcare professionals to sustain their roles financially. This issue is compounded by the migration of staff to the private sector or other employment sectors due to inadequate pay and working conditions.

“ A lot of the nurses and therapists I know have gone to private practice as they can’t afford to work for the NHS any longer.

The quality of care has noticeably declined, with patients frequently receiving fewer comprehensive services than before. Budget cuts and resource limitations mean that essential medical supplies and services are often inadequate.

“ Products used by the NHS have been reducing in quality as they are having their own budgets squeezed.

Participants reported that essential items and their treatments are being deprioritised or delayed. This includes critical medications, medical supplies, and even fundamental care services.

For instance, one respondent highlighted how the reduced quality of incontinence pads and dressings has directly affected their daily care routine and comfort. Another described how medical supplies and medicines, which are vital for managing chronic conditions, are frequently in short supply or completely unavailable.

Continuity of care has been severely disrupted, with patients often seeing different doctors at each appointment, if they manage to get one. This lack of consistency can lead to miscommunications and a fragmented approach to healthcare.

“ I don't think I've ever met my GP; she's just a name on a piece of paper that's supposed to coordinate my care.

Participants have reported a severe lack of continuity in their healthcare provision, which has significant implications for their overall treatment and well-being. The administrative burden placed on patients has also increased. Several participants mentioned that they often have to advocate for themselves, conducting their own research to ensure they receive appropriate referrals and treatments. This not only adds to their stress but also highlights systemic inefficiencies within the NHS.

Comment

1 Appointments are difficult to get to meaning I haven't been able to have scans etc.

2 More staff are leaving because they can't live on the salary the government gives them, which reduces continuity of care, staff satisfaction, waiting lists and service.

3 It's all about the money. We don't have confidence that the NHS is there for us anymore. Pensioners and disabled [people] are at the bottom of the pile.

4 Some of the medical supplies and medicines used for my daughter have been in short supply and sometimes unavailable.

5 Everything is such a fight. There's no automatic referral to services. In some cases I have had to do my own research and go back to my GP pointing out my eligibility to get referrals.

6 The NHS has been a mess since Brexit and worsened by Covid. The quality of care is appalling. I feel for those working for the NHS as they are suffering from lack of resources and staff and are not able to provide the correct level of care.

7 Access to health care is very challenging. There are no NHS dentists locally, GP surgeries put barriers in place to access in-person care, and I constantly have appointments with consultants cancelled. Mental health care is non-existent.

8 Although I have had conditions that would have required clinical attention, the chances of getting that attention are so small I have had to use home remedies. For example, extracting my own teeth or loose fillings.

9 My son has regular visits to hospital as he also has a chronic health issue which requires regular and ongoing interventions. We have been at hospital during strikes, the staff do an amazing job to keep procedures happening and care to patients, but it's a huge strain on the staff and you can see the pressure they are under.



There are too few doctors and nurses. Those who remain are stressed and overworked.



The cycle of cost-of-living disparity

The cycle of cost-of-living disparity is a critical framework for understanding the interconnected challenges that disproportionately affect disabled people and carers.

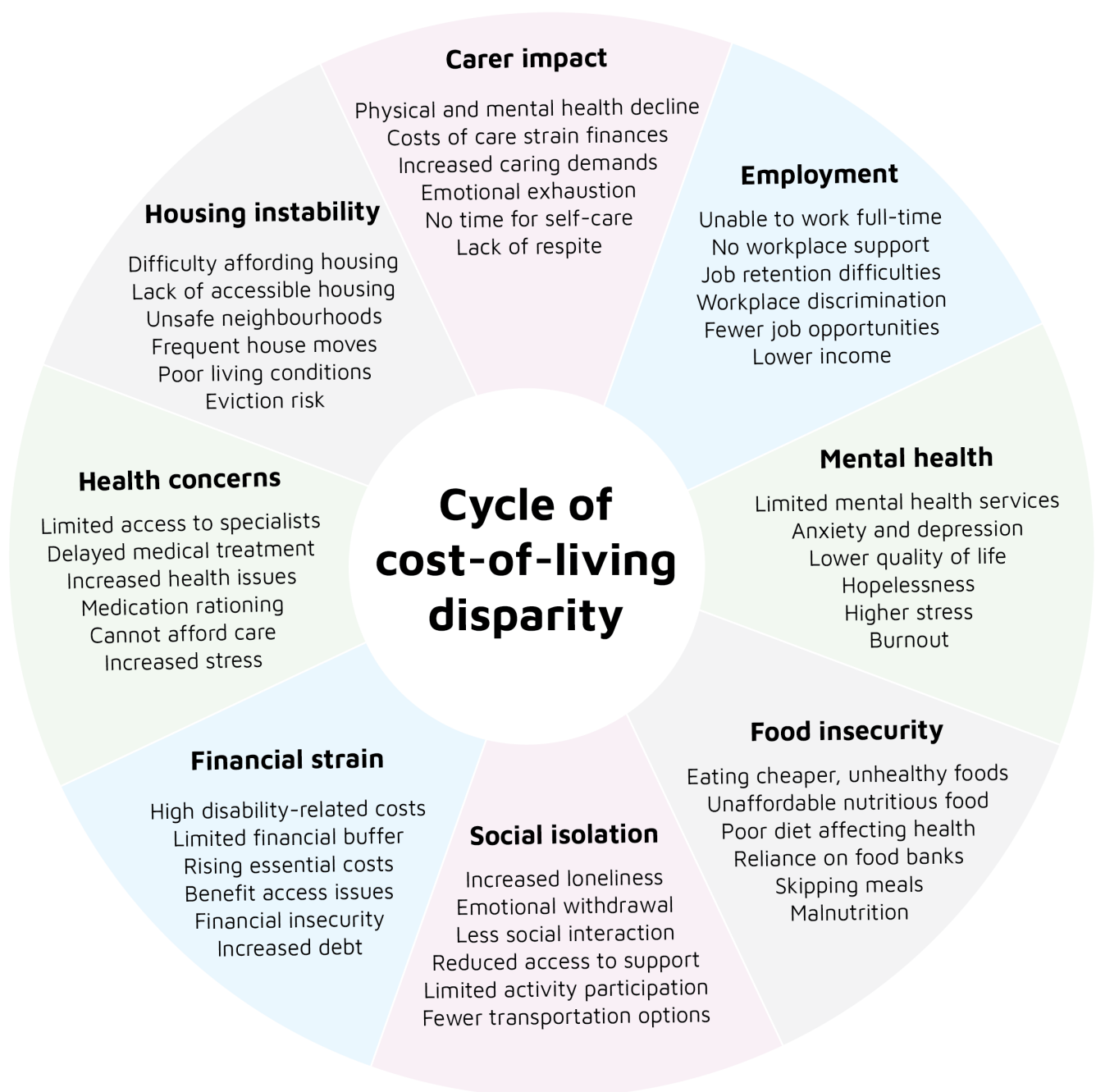
Financial constraints force tough choices between heating, eating, and care, leading to declines in physical and mental health. This often results in social isolation and housing instability, further exacerbating the challenges that disabled people and carers face.

“Poverty and deprivation are not protected characteristics, but there is a high social cost of failing to address the health inequalities they cause, resulting in higher morbidity and mortality for tens of thousands of people, particularly disabled people and other minorities, which has been increasing over the past decade, along with other social ills, reflected in overburdened services.

The cost-of-living crisis, triggered by worldwide events, has enormously magnified an underlying trend which has eroded our resilience. We cannot afford to continue with short term measures that fail to fix underlying problems, especially those that fail to address disparities. What we need now is effective focused targeted action and improved governance.

- Eleanor, steering group member

By examining the cycle of cost-of-living disparity, our research illuminates the urgency of systemic changes and enhanced support mechanisms. It emphasises the need for comprehensive solutions that address the financial needs and the social and health-related challenges contributing to this cycle. A holistic approach is necessary to break the cycle and improve the overall well-being and quality of life for disabled people and carers.



Recommendations

The research conducted by Independent Lives has uncovered a broad spectrum of issues arising from the cost-of-living crisis, indicating there is no straightforward solution.

When asked, “Is there anything you would like to see offered to ease the impact of the cost-of-living on disabled people and carers?” survey participants provided a variety of suggestions. These ranged from capping care contributions to help with fuel and heating bills.

Specifically, eight participants highlighted the necessity of increasing the Carer’s Allowance, with one suggesting it should match the living wage for the hours worked. Additionally, many participants criticised the current benefits system, particularly the Personal Independence Payment (PIP). They described the application process as both frustrating and anxiety-inducing.

One interviewee told us:

“ You’ve got somebody that’s sitting at the table looking at your application form that doesn’t even know anything about your particular disability. They’re not a professional in that field and they don’t understand what your disability is. I think that definitely needs to be looked at.

Furthermore, many offered concrete suggestions such as reducing payroll fees for Direct Payments, providing discounts on social activities for disabled individuals, and practical benefits like exemption from MOT costs.

However, some participants were either unable or unwilling to offer

suggestions. One noted:

“ Yes (there is something that can be done to help), but I don’t have the energy to even think of what kind of help we need.

35% of participants

Benefits support

A significant number of responses focus on the need for increased financial assistance. Suggestions include increasing Disability Living Allowance (DLA), Personal Independence Payment (PIP), and Carer’s Allowance. Some participants call for specific financial support such as additional cost-of-living payments or adjustments to existing benefits.

20% of participants

Living expenses

Many responses highlight the need for assistance with daily living expenses, including capped or reduced rates for utilities like electricity and gas, especially for homes requiring medical equipment. There are requests for help with heating, food (including food bank vouchers and food stamps), and other essentials like transport and specific dietary items.

12% of participants

Health and social care

There are repeated calls for more affordable health services and improved social care. Participants suggest caps on care contributions and emphasise the need for rehabilitation and family services. A common theme is the need for the healthcare system to give more consideration to doctors’ opinions over those of non-medical professionals.

10% of participants

Discounts and concessions

Participants suggest various forms of discounts such as on public transport, social activities (cinema, eating out), and necessary services like MOT costs.

8% of participants

Improved access

Suggestions include more user-friendly and efficient access to services, stopping benefit cuts, and simplifying the application processes for benefits which many find cumbersome and stressful.

Recommendations for the NHS

Our interviewees provided a range of insightful suggestions on how the NHS could enhance its support for disabled people amidst the cost-of-living crisis. These suggestions emphasise a need for holistic care approaches, improved mental health services, better equipment provision, enhanced compensation for healthcare professionals, and stronger patient engagement.

One recommendation is for the NHS to adopt a more holistic approach to healthcare, integrating services such as physiotherapy and orthotics into care plans. This would not only address the immediate symptoms but also the underlying causes of health issues, supporting patient independence and potentially reducing future healthcare costs.

The urgency of improving access to mental health services was another critical point raised, particularly the need for faster access to these services for children. The current lengthy waiting times can exacerbate mental health issues, with severe implications. Investing in mental health infrastructure is seen as essential for providing timely and adequate support, which can also enhance physical health and

overall motivation.

“ Mental health services. Absolutely. I’m surprised still with how long it takes to get into certain mental health services. For children, it’s impossible. It’s quite frightening. I actually think it’s quite dangerous how slow it is to get a child into the mental health service.

Another practical suggestion involves the NHS taking on the manufacturing of disability aids to circumvent the high costs imposed by private companies. This change could make essential equipment more affordable and accessible, directly benefiting those who need these aids to manage their daily lives.

Enhanced compensation and better retention strategies for junior doctors and other NHS staff were also emphasised. Fair compensation is crucial for retaining skilled professionals and ensuring that patients receive care from motivated, respected personnel.

“ I personally think they should pay the junior doctors what they are asking for... I don’t want to be seeing a doctor who’s stressed and doesn’t particularly want to be there because they feel undervalued.

Finally, genuine patient engagement was highlighted as necessary for real change. While many feedback mechanisms exist, they often feel like mere formalities rather than earnest attempts to understand and address patient concerns. Effective change requires the NHS to not only listen but also act on the feedback provided, tailoring services to meet the real needs of those they serve.

Comment

1 A council tax reduction (should be) implemented when you're still caring but have underlying entitlement to Carers Allowance and E.S.A. combined.

2 Discounts on things like cinema, free use of buses, days out, eating out. Coffee vouchers, exemption from MOT costs, food vouchers for any carer or PIP claimant.

3 Additional cost-of-living payment.

4 More government support financially. Stop the war in Ukraine and stop supermarkets shrinking our foods and still charging us even more for the products. Take responsibility for water quality and petrol prices.

5 Social tariff for fuel bills.

6 I used to get a warm home discount on my heating bills, but no longer receive this.

7 Help with cost of heating.

8 Help with things like petrol, essential items such as dietary specific foods. Specific to the needs of my disabled son – school an hour away, barely any SEND days out anymore, no compass card.

9 Food bank vouchers.

10 Increased DLA / PIP / Carers allowance.

11 Carers allowance is insulting it is so low. This needs to be increased to pay carers the minimum wage at least for the hours they spend caring.

12 Advice on how to keep my home warmer.

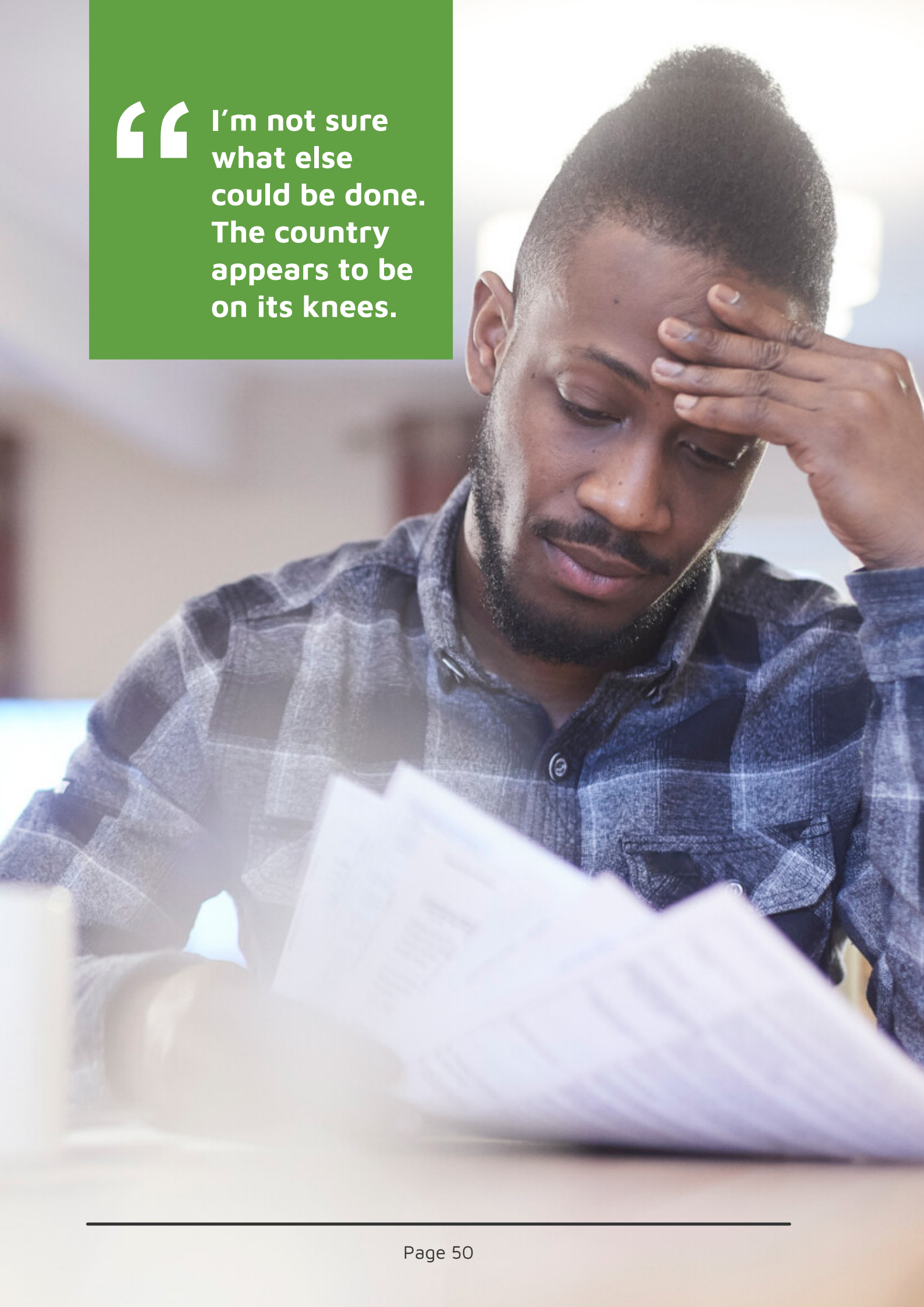
13 Capped gas and electric prices for those who have to stay home caring.

14 I'm not sure what else could be done. The country appears to be on its knees.

15 Funding for respite and for longer term support from organisations such as My Network Plus.



**I'm not sure
what else
could be done.
The country
appears to be
on its knees.**



Conclusion

In this report, Independent Lives has aimed to amplify the voices of disabled people and carers in Sussex.

Recognising the lack of research on the real-life impact of the cost-of-living on this group, our study was designed to fill this gap. Our findings provide decision-makers with tangible evidence and insights into the impact of the cost-of-living, along with actionable recommendations on how to address these challenges.

The collected experiences of disabled people and carers in Sussex revealed the following four key pressure points:

- 1.** Disabled people and carers have been forced into making difficult decisions between heating, eating, and care.
- 2.** Few options were available to participants, often contributing to them feeling trapped.
- 3.** Participants often highlighted how they were 'surviving, not thriving'.
- 4.** Participants were suffering the consequences of the cost-of-living crisis, which has had a devastating impact on their mental health.

The research also uncovered a cycle of disparity that exacerbates the impact of the cost-of-living. This cycle includes health concerns, housing instability, carers on the verge, employment challenges, mental health issues, financial strain, food instability, and social isolation. Each of these areas of disparity compounds the others, creating a complex web of challenges.

The research participants were asked for their views on what changes could or should be made to enable disabled people and carers to better navigate the cost-of-living crisis.

These views resulted in a wide range of suggestions and recommendations. These recommendations fall into two main areas: one focusing on what the NHS can do to help address the impact of the cost-of-living on disabled people and carers, and one set of recommendations, more broadly.

Following this research, Independent Lives will continue to work with the NHS, local authorities, the voluntary sector, disabled people, and carers to address the disparities identified and support the implementation of the recommendations.

If you would like to be involved in this work moving forward, please email: **info@independentlives.org**.

Acknowledgements

Thank you to everyone who has taken part in our research. Your contributions have been invaluable and deeply appreciated.

Each response has not only enriched our understanding but has also shed light on the real challenges faced by many within our community. The willingness of participants to share their experiences and insights has played a vital role in guiding our efforts. It is through their voices that we can bring to light the issues that matter most and advocate for meaningful changes.

We would like to extend a heartfelt thank you to our steering group members who have volunteered their time to help us ensure our research stayed on track and remained true to the experiences of disabled people and carers.

We would also like to thank NHS England, who along with the University of Reading and the Scottish Community Development Centre developed the project and allowed us to begin this journey. Thank you also to all of the other Community Participatory Action Research participants whose community research projects will each bring value and insight to the communities they represent.



**University of
Reading**

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Independent Lives is a user-led charity working to change the lives of disabled people, people with support needs and carers. Our vision is for a fair society where everyone can participate and has the opportunity to fulfil their potential.



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