

Shine a Light on Care: Listening to Parents and Carers



Shine a Light on Care: Listening to Parents and Carers Key Insights and Recommendations to Support Carers in Bristol and the West of England

Authors:

Siobhan Canavan from NOSY ABOUT HUMANS with additional research by Jess Brake on behalf of Bristol Women's Voice and the Value the Caring Economy Alliance.

About the author:

Siobhan is a qualitative researcher with a background in Documentary Photography. One medium was swapped for another with the consensus that she could still investigate, be curious and remain nosy.

Siobhan strives to understand people, their wants, hopes, needs and behaviours. In doing so she has been lucky enough to work on a variety of different topics for big and small brands. From long-term UX studies on technology and social media to deep ethnographic research on food, babies, care delivery, dating, sex, well-being, personal products, finance, debt and pain (and most things in-between).

Siobhan is founder and researcher of NOSY ABOUT HUMANS.

Design:

Raisha Jesmin and Claire Charras, Bristol Women's Voice

About the Value the Caring Economy Campaign

Across Bristol, women have told us, loud and clear, that economic inequality is their number one concern. And it's no surprise. Prices for food, fuel, and housing are continuing to rise.

The lack of caring infrastructure is a key driver of women's economic inequality. The lack of affordable childcare and flexible working means women often leave the work force and/or reduce to part time. The costof-living crisis isn't gender-neutral. It's hitting women with caring responsibilities the hardest.

In response, we formed the Value the Caring Economy Alliance – a coalition of nine community organisations. Together, we're calling for serious investment in the backbone of our society: the caring economy. That means better childcare, stronger support for social care, fair pay for care workers, and flexible working that lets people care without sacrificing income.

The Value the Caring Economy Alliance is made up of: Bristol Women's Voice; the Economic Taskgroup of the Women's Commission; Bristol Black Carers; Carers Support; Bristol Women in Business Charter; Women's Budget Group; Co-Produced Care; WECIL and Chinese Community Wellbeing Society.

To find out more about our work, please visit: https://www.bristolwomensvoice.org.uk/caring-economy/



















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Executive Summary

This report, authored by Siobhan Canavan for Bristol Women's Voice and the Value the Caring Economy Alliance, presents findings from comprehensive research into the experiences of unpaid carers in Bristol. The study engaged more than 250 women through a survey, ten lantern workshops, six in-depth interviews, and one focus group to understand the challenges faced by those caring for children, elderly relatives, and Disabled family members.

Research highlights a stark national context: 1.2 million unpaid carers in the UK live in poverty, with 400,000 in deep poverty. Bristol mirrors these trends, with 34,000 carers in the city and 42% of full-time carers extremely worried about heating costs. Across 83 quality-of-life indicators, full-time carers consistently fare worse than city averages.

1. Financial Hardship

Carers face severe financial pressures due to inadequate support structures, benefit cuts, and the inability to maintain full-time employment. Many struggle with costs of specialist care, equipment, and basic living expenses while supporting vulnerable family members.

2. Employment Challenges

Carers encounter significant barriers in the workplace, including inflexible working arrangements, unsupportive employers, and limited career progression opportunities. This particularly affects women, who are seven times more likely than men to become economically inactive due to caring responsibilities, resulting in reduced pension contributions and long-term financial insecurity.

3. Childcare Access

Parents, especially those with children with special educational needs and disabilities (SEND), face limited access to affordable, high-quality early years provision. This forces many to abandon employment or career advancement, creating a cycle of economic disadvantage.

4. Lack of Breaks

Carers report feeling overwhelmed and exhausted, with minimal access to regular breaks, emergency breaks, or mental health support. The absence of short-term and longer-term relief options leaves carers without essential recovery time.

5. Social Isolation

Only 27.8% of unpaid carers in Bristol report having adequate social contact, representing a significant decline from 46.2% in 2012/13. This isolation is particularly acute among Asian/Asian British carers, contributing to deteriorating mental health.

6. Healthcare Barriers

Both carers and those they support face difficulties accessing timely healthcare appointments. Carers often sacrifice their own health needs, with 44% delaying treatment due to caring responsibilities.

7. Discontinuity of Support

Long-term carers experience fragmented support systems, particularly during transitions from children to adult services. High staff turnover (31% in Bristol's adult social care) creates instability and forces carers to repeatedly explain their situations to new professionals.

8. Legal and Advocacy Support

Carers struggle to navigate complex legal, welfare, and healthcare systems without adequate advocacy support. Access to legal advice remains limited, with 70% of the UK population lacking access to community care legal aid providers.

Impact and Implications

The undervaluation of the caring economy has profound economic consequences. An estimated £3.64bn in output is lost across Gloucestershire, Wiltshire, Bath and North East Somerset, and Bristol due to caring responsibilities preventing women from working. Nationally, unpaid care is valued at £162 billion, nearly equivalent to NHS spending. The gendered nature of caring disproportionately affects women, particularly those from Black and minoritised communities and Disabled women.

The COVID-19 pandemic has intensified these challenges, with 38% of carers providing increased care due to reduced or closed services. This trend, combined with rising living costs and benefit cuts, has created an unsustainable situation for many families.

Recommendations

The full report presents tangible recommendations across key statutory sectors and employers. A summary of these is below:

National government should simplify the benefits system, introduce statutory paid care leave, address long-term financial impacts on women carers, and expand childcare eligibility criteria.

Regional and local authorities must prioritise carers in financial support allocation, improve information access, commission targeted outreach, develop employment standards for caring-inclusive workplaces, invest in respite services, and fund legal advice services.

Healthcare systems need to expand mental health services for carers, implement carer liaison services, and train healthcare providers to understand carer needs.

Employers should implement mandatory carer support training and develop inclusive workplace policies that accommodate caring responsibilities.

Conclusion and Next Steps

The report emphasises that these findings are not new - similar recommendations have been made repeatedly. What is needed is decisive action rather than further research. The Value the Caring Economy Alliance commits to updating online service directories, collaborating on employment standards, supporting women's economic wellbeing, and promoting carer-inclusive workplaces. We call upon decision-makers to also commit to action.

The research demonstrates that addressing carer needs requires coordinated effort across sectors, recognition of care's intersectional and gendered nature, and sustained investment in support systems. Without meaningful intervention, the current crisis in the caring economy will continue to deepen, with devastating consequences for individuals, families, and the broader economy.

The message is clear: Bristol's 34,000 carers need immediate, comprehensive support to escape poverty, isolation, and ill health while maintaining the essential care that underpins community wellbeing. The time for action is now.

Introduction

Across the UK, millions of people provide unpaid care for children, older people, Disabled people and those with long-term health needs. These carers form the backbone of our communities and our economy - but their contribution remains largely unrecognised, undervalued, and under-supported. As a result, many carers (individuals who provide care and support for their family member) find themselves trapped in cycles of hardship and poverty, often invisible to wider society and government policy.

National data reveals the stark reality. In 2023, 1.2 million unpaid carers in the UK were living in poverty, with 400,000 in deep poverty. The poverty rate among unpaid carers was 50% higher than those who did not provide care, and for those caring more than 35 hours a week, the poverty rate more than doubled (43%) compared to non-carers (18%). Carers aged 25–44 face the highest rates of poverty, and two-thirds of unpaid carers on Universal Credit live in poverty. [i]

These national trends are sharply mirrored in Bristol. According to the 2021 census there are 34,000 carers living in Bristol, and the City Council Quality of life survey found that in 2022, 42% of full-time carers were extremely worried about keeping their home warm, 20% found it difficult to make ends meet and were experiencing moderate or serious food insecurity. [ii]

Across 83 indicators full-time carers fared worse than the city average: 27% had an illness or health condition which limits day-to-day activities; almost half (45.3%) said caring responsibilities prevented them from leaving their home when they wanted to; almost half never participated in cultural activities, 21.7% were victims of disability discrimination or harassment last year; 19.4% lacked the skills or confidence to use the internet.

For many, the intersecting pressures of the caring role and responsibilities, low or insecure income, lack of flexible work, and rising costs, particularly resulting from the COVID-19 crisis and the on-going cost-of-living crisis, are compounding.

Caring is an intersectional and gendered issue. Unpaid caring responsibilities disproportionately fall to women, particularly Disabled women and women from Black and minoritised communities. Workingage women on average do 1.5 fewer hours of paid work and 1.8 more hours of unpaid work per day than men. More than a third of carers providing over 50 hours of care per week are Disabled in both England and Wales.

This responsibility for unpaid care has a direct impact on women's economic well-being: research from across the UK shows that women are twice as likely than men to give up paid work to care, [Y] and are more likely to be pushed out of the labour market due to those caring responsibilities.

A 2021 survey of older carers in Bristol revealed that over one-third of the 180 respondents received no help from anyone else. Of those, half had been caring for more than four years, and a quarter for over a decade. Alarmingly, 29% had received no formal support, and nearly two-thirds had never had a carer's assessment. [VIII]

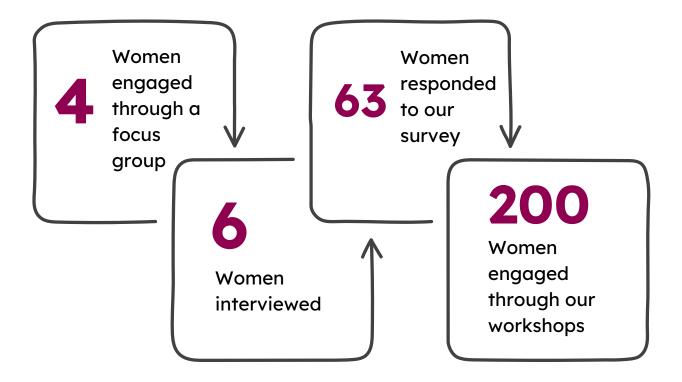
The undervaluing of care can also be seen throughout the care sector, which is underfunded and low status. Care work generally lacks good pay and conditions, career progression and training opportunities, meaning there is a challenge to retain skills and experience, leading to a high turnover of staff and lack of care consistency for those who are cared for.

This report aims to bring forward the voices and lived experiences of carers and parents in Bristol, drawing from a series of open-response survey questions focused on what needs to change.

From access to affordable childcare and carers breaks, to workplace flexibility and legal advocacy, the responses reveal not only what's broken, but also what could be done to fix it.

Through their insights, we identify eight key findings that can help inform better policy, services, to support the carers and those they care for.

Engagement Methods



The data presented in this report comes from:

• An anonymous 13-question survey focused on four main areas regarding the support available to parents and carers in the area.

Briefly:

- (1) understanding the impact of being a carer;
- (2) what support was desired;
- (3) impact this support would make; and
- (4) specific requests for support in Bristol.

This was distributed to parents and carers across Bristol – 63 responders.

- Ten lantern workshops led by Bristol Women's Voice and Lamplighter Arts, attended by around 200 women whose feedback was captured.
 These were delivered in collaboration with:
 - Mothers for Mothers, Hartcliffe
 - Dhek Bhal, Barton Hill
 - Sadaga, Stapleton Road, Family Christian Centre
 - Bring Your Own Baby Choir, St George
 - Chinese Community Wellbeing Society, Fishponds
 - Winter event, Southmead
 - Lantern & puppet making, Bristol City Centre
 - o Two community events for carers, Broadmead
 - o International Women's Day, Bristol City Hall

The workshops focused on the experiences and impact of caring that the individuals faced. All workshop participants were encouraged to share their experiences with their peers while making lanterns for a lamplit procession in Bristol town centre, coordinated by Bristol Women's Voice on 22 March 2025.

- Six one-hour in-depth interviews with carers in the Bristol community.
- One four-person, focus group with carers in the Bristol community

These explored the impact that Bristol carers faced in more detail and gave us a greater understanding and nuance to the issues that many carers experienced.

Responses were analysed for recurring themes and concerns. The sample includes individuals caring for children with special needs, elderly parents and Disabled family members.

Key Findings and Insights

1. The Need for Improved Financial Support

Context

Nationally, data shows almost 30% of carers are themselves Disabled and changes to the benefit system can impact income from both Personal Independence Payments and Carers Allowance.

Caring responsibilities have increased since the pandemic, and 38% of carers are providing more care because of local services reducing or closing. Carers are using their time, resources and finances to prop up a system that is letting both them and those that they care for down.

What parents and carers told us

A large portion of respondents voiced a significant concern regarding the financial pressures faced by parents and carers. Many felt that current financial support structures are insufficient, especially for those caring for children with additional needs, elderly relatives, or Disabled family members.

Common suggestions to support those facing financial strain included increased financial assistance, tax breaks, and welfare support designed specifically for all types of carers.

Financial strain was identified as a major challenge, with many carers struggling to manage both caregiving and the cost of living. Several parents and carers noted that their incomes were insufficient to cover the cost of specialist care services, medication, or necessary specialist equipment. The benefits cuts will result in severe financial shortages for carers who are themselves Disabled; there is also a gap between carers who dedicate time to supporting, but who are not yet in receipt of the 'care label'.

In the words of carers

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We are on the lower end of earnings as a family, but we still have much more than others and yet we still struggle.

- A lot more financial support for carers and parents. My mother cannot work since she looks after both my sister and grandmother, who require 24/7 care... we struggle a lot financially.
- I'd like to see so much more recognition of carers and maybe carers allowance on top of your income because care doesn't stop if you're at work. Whether it's part-time or full-time employment, your caring responsibilities don't magically disappear.

Recommendations

For National Government

• **Simplify the benefits system** to ensure timely, accessible support without excessive bureaucracy, especially for carers and low-income families.

For Bristol City Council and all local authorities

- Prioritise carers facing financial hardship in the allocation of the Household Support Fund. This should explicitly include carers of adults and carers of children with SEND (Special Educational Needs and Disabilities).
- Improve access to information about financial support for carers by simplifying content, ensuring clarity, and producing printed materials to address digital exclusion.
- Commission targeted outreach to identify and engage carers who may not be accessing existing support.
- Fund carer support organisations to deliver financial advice and practical assistance tailored to carers' needs.

2. Supporting Carers in Employment: Flexibility, Progression and Understanding

Context

Employers may not always recognise the specific needs of their employees who are carers. This lack of awareness can lead to misunderstandings and, in some cases, discrimination or unfair treatment. In cases where carers have been supported by their employers, it has alleviated some of the stress and been transformational, not only for their experience of caring but their confidence levels and overall career trajectory.

Caring responsibilities - particularly for children or family members with disabilities or complex ill-health needs - often conflict with working hours and practices. This is further felt by those in lower-paid or hospitality type roles, as traditionally their employers have a lower ability to be flexible compared to more corporate or office jobs. Additionally, many carers are forced out of employment or into underemployment, with serious consequences for their income, wellbeing, and pension contributions.

The West of England Combined Authority's Good Employment Charter includes a commitment to flexible working. The Women in Business Charter, which provides a more supported and audited process for signatories, also focuses on flexible working. However, the sign-up to either of these charters is voluntary. In Manchester, there's a move to embed the Good Employment Charter within public procurement processes so that all businesses bidding for public contracts will receive a social value weighting if they are signatories. If the West of England Combined Authority were to adopt a similar approach, it would encourage inclusive working practices across the sector.

Social care policies must be considered alongside rising state pension ages. From 2026–27, the age will increase to 67, saving the government an estimated £10.3 billion annually.^[ix]

These savings could fund local social care, protect disability benefits, and raise Carers Allowance.

However, raising the pension age will likely harm carers' health and well-being, especially in deprived areas where health inequalities and reduced life expectancies are stark. For instance, women in Hartcliffe may receive a pension for just five years due to poor health, while those in wealthier areas like Westbury could receive it for 18 years.^[x]

The gender imbalance is also notable; men often retire earlier by drawing private pensions from age 55, carers have no choice but to work for longer as they have not been able to build up this security. This is despite the fact that unpaid carers are also often in paid employment. One in three of all NHS staff are unpaid carers [xi], and care workers make up the largest group of night workers.

In 2021 the value of unpaid care was estimated to be £162 billion ^[xii], 29% more than in 2011 and almost as much as the NHS. If unpaid carers stopped caring, it would take 4 million paid carers to replace the care they give.^[xiii]

It is important to note that the census found there were 128,200 young unpaid carers aged between 5-17 years caring for older generations. [xiv] Schools need to be aware of their circumstances.

Women are seven times more likely than men to become economically inactive due to care (ten times more likely in their thirties)^[xv] and an estimated £3.64bn in output is lost across Gloucestershire, Wiltshire, Bath and North East Somerset, and Bristol due to caring responsibilities preventing women from working. ^[xvi]

What parents and carers told us

Many carers and parents reported that remaining in paid work is critical for their financial stability, identity, and mental health, but they face significant barriers to both securing and retaining employment. These include a lack of flexible working options, unsupportive or unaware employers, rigid schedules, and poor understanding of the demands of caring roles.

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Respondents stressed that employment support must go beyond basic flexibility to include real career progression, leave entitlements, and acknowledgment of the realities they face.

Several responses emphasised the need for training programmes for employers to have an insight and understanding about caregiving issues. By fostering a better understanding of the challenges faced by parents and carers, employers can create a more supportive work environment. Greater awareness is needed for young carers or those in lower-paid, more unstable ad hoc or hospitality-type roles, who still require flexibility.

In the words of carers

- I had to give up my job because I couldn't find childcare that could meet my son's needs. I didn't want to—but there was no other option.
- If employers understood what we're juggling, they'd offer more than words—they'd give flexibility that actually works for carers.
- We're told to ask for flexibility—but when we do, we're made to feel like a problem. That has to change.
- Because of my caring responsibilities, I've done parttime work here, there, and everywhere, and I've got no pension pot built up. It's all little bits here and there, so I'll have nothing to draw on later in life
- I think it affects women more than men, because women tend to be doing the caring of children, of the elderly, of partners, and our pension pots become minimal, non-existent.

- I used to be the CEO of a small charity, but I had to step down because of my caring responsibilities to my son who struggles with autism. I could be working in more senior roles and earning more money, but I am limited by my family life.
- My employers can be a little bit prickly about my need to work from home sometimes to look after my mother, which can definitely be a challenge.
- When my eldest son dropped out of school, I had to ask for three weeks of unpaid leave because I didn't have any annual leave left.
- My boss just doesn't get it. I've had to lie about why I'm off because I know they'll see me as unreliable.
- I was told I couldn't go part-time or adjust my hours, even though I'm a carer. It made working impossible.
- There needs to be better training around the needs of carers. When I go to carers' meetings nowadays, I'm hearing the same stories of things I went through 15, 16 years ago. It's shocking and disappointing that, unfortunately, history keeps repeating itself. Families are still being failed.

Recommendations

For National Government

- Address the long-term financial impact of caring on women by introducing measures to compensate for lost pension contributions and income protections.
- Introduce statutory paid care leave.
- Widen the eligibility criteria for the 30 funded hours of childcare to include parents in education and training.

For the West of England Combined Authority (WECA)

- Co-create a region-wide standard for flexible working and caring employment in partnership with carers.
- Review and update the Good Employment Charter to embed this standard and promote inclusive workplaces for carers and parents.
- Require adherence to the caring employment standard as a condition for procurement and commissioning.
- Develop training with the Caring Economy Alliance and carers to help employers understand caring roles and responsibilities, fostering a culture where carers are supported rather than overlooked or penalised.

For All Employers (including regional and local authorities)

- Implement mandatory carer support training for all staff and managers to build understanding of carers' needs in the workplace.
- Ensure workplace policies are inclusive of caring responsibilities, creating a proactive and supportive environment for employees who are carers.

3. Access to High-Quality, Culturally Appropriate, Affordable Early Years Provision

Context

Early years education is undervalued and under-resourced in the UK. Children are the future and their early years are the most important time in their development, yet it continues to be treated as an add on or a luxury. Evidence from the review of the Surestart Programme showed better educational and health outcomes for the children who benefitted from it. [xvii]

Despite this those who work in this vital service are underpaid and the rates the government pays to subsidise this essential service is below that which is needed to maintain the required high standards.

This means that parents with young children are faced with unaffordable costs and inadequate provision of childcare both for under 5s and access to after-school and holiday childcare, which impacts their ability to get, keep and maintain a career. This severely impacts on their finances, both in the present and in the future. Universal childcare would provide £46.8M additional income to parents in the region, according to West of England Combined Authority figures.

Furthermore, parents with SEND children face unique challenges in accessing childcare that meets their child's specific needs. The lack of suitable provision often forces parents to take on caregiving roles full-time, which can lead to emotional and financial strain.

What parents and carers told us

Affordable, accessible, high-quality culturally relevant early years provision, especially for parents with children with special educational needs (SEND), was highlighted as a significant challenge to women's financial security and emotional well-being. Respondents expressed frustration at the lack of available spaces and the high cost of care. For many, the inability to afford adequate childcare made it difficult to maintain full and part-time employment or take necessary breaks.

In the words of carers

- Childcare is extortionate and doesn't fit around school hours. And when your child has additional needs, it becomes even more difficult to find appropriate care.
- I had to give up work because I couldn't find affordable childcare that would accommodate my son's autism.
- I'm desperate to get back into work but the cost of childcare wipes out anything I'd earn. It's a no-win situation.
- We need better facilities for Disabled children and adults, changes to the education system to better support neurodivergent children and their parents.
- For me, I was looking more long-term, well thinking that what she gets into, she would be there long term. And so for me, I felt that she needed to be with her peers. And the place we visited, they were a lot older. They were like, 40s, 50s, 60s. I didn't want her to be with people in that age bracket because I thought, well, she's just a young person.

Recommendations

For the WECA, Bristol City Council and all local authorities

• Invest in training and career progression for Early Years workers, including funding for backfilling posts to enable staff to pursue qualifications such as Level 3.

• Subsidise wages for low-paid Early Years workers and apprentices, especially in disadvantaged areas, to improve retention and workforce stability.

For Bristol City Council and all local authorities

- Expand access to inclusive services such as after-school clubs and trusted care activities, particularly for children with SEND and other vulnerable groups.
- Provide tailored financial guidance for parents, helping them navigate and access available financial support schemes.

For all employers (including regional and local authorities)

- **Promote workplace-based childcare facilities** to support working parents and improve work-life balance.
- Offer and actively support flexible working arrangements to accommodate the needs of parents and carers.

4. The Importance of Breaks for Carers and Health Support

Context

In 2025, Bristol City Council, in partnership with local carers organisations, published the findings of focus groups with 70 carers to understand what breaks they want and need. The report concluded that carers need a range of breaks. The breaks that carers need are a lot more diverse than most respite services and carers' Direct Payments offers, which tend to be central to adult social care commissioning and provisions.

The need for short regular breaks, short-term and longer-term emergency breaks, and overnight cover is particularly acute. [xviii] The lack of regular breaks, particularly short breaks and emergency breaks, and mental health support is a critical issue. Respondents called for easier access to counselling services, mental health support, and dedicated respite care options.

What parents and carers told us

Many parents and carers reported feeling overwhelmed, physically and emotionally exhausted.

In the words of carers

- I haven't had a break in over a year. I'm constantly on edge, exhausted, and feel like I'm drowning.
- There's zero mental health support for carers. We are expected to carry on without rest, and it's breaking people.

- Even a few hours of respite a week would be lifechanging. Right now, I can't even go to the shops alone.
- When I did counselling a year ago, I found it very helpful, but it was really expensive so I had to give it up.
- I can't commit to [social] things that often, because I just don't know what I'll be doing. Caring can be very unpredictable.

Recommendations

For Bristol City Council and all local authorities

• Invest in care services that provide regular breaks for carers, including both short-term and extended respite options.

For the Integrated Care Board

- Develop and deliver training for healthcare providers to better understand and respond to the mental health needs of carers.
- Expand access to mental health services for carers, including online counselling and support groups, ensuring ease of access and flexibility.

For the Voluntary, Community and Social Enterprise Sector

• Explore, document, and share good practice in supporting carers to access the services they need, with a focus on removing barriers and improving coordination across sectors.

5. Social Support and Peer Networks Are Vital

Context

Many carers feel isolated, particularly those who do not have friends or extended family nearby. Peer networks and support groups can be a lifeline, offering advice, shared experiences, and emotional reassurance.

In 2023/24, only 27.8% of unpaid carers in Bristol reported having as much social contact as they desired. This is a significant decline from 46.2% in 2012/13. Bristol's figure is lower than the English average of 30%. It is notable that isolation is also an intersectional issue, with carers from of Asian/Asian British carers in Bristol reporting less social contact with 79% reported being isolated. Similarly, female carers are more likely to report isolation than male ones and no Bristol carers aged 35-44 felt they had enough social contact. [xix]

What parents and carers have told us

Social isolation was another common theme, with many carers reporting a lack of social interaction outside of their caregiving roles. The need for peer networks, community groups, and other social support mechanisms was emphasised, as these networks provide emotional support and practical advice.

Some had based pivotal life decisions on the accessibility of social and peer support that would be embedded into their locality, for example university campuses or towns and cities.

In the words of carers

- Being a carer is incredibly isolating. I don't know anyone else in the same situation and it's really lonely.
- The only place I feel understood is in my carers' support group. It's a lifeline.

- I've lost touch with friends because they don't understand what my life looks like now.
- Part of the reason for choosing Bristol University was because they had a young carer network.
- [Because of caring] I can't see my friends. I sometimes get jealous that I can't do the things they do. We can't even go out for day trips at the moment, because we can't leave Dad, and can't get him and all the equipment in the car. I can't push two wheelchairs either, so it's very limiting at the moment and that does have an effect on my mental health.
- My carers' support group is really important to me.

 It's where I can be myself and feel understood.
- It's difficult to maintain friendships with people who don't understand what you're going through. It feels lonely and isolating.

Recommendations

For Bristol City Council and all local authorities

- Explicitly recognise the intersectional and gendered nature of care across adult social care and funding strategies.
- Continue and expand funding for local support groups for parents and carers, particularly those with specific caregiving needs such as parents of children with SEND, elderly carers, young carers, and those supporting individuals with complex health conditions.

6. Gaps in Healthcare Access and Support

Context

Carers often sacrifice their own healthcare needs to prioritise those they care for. Furthermore, there is a lack of understanding about the specific healthcare needs of carers, leading to barriers in accessing services.

A research report that involved 10,751 people who are currently providing care, found that 61% of carers said they needed more support to be able to look after their health and wellbeing and 44% said they had put off health treatment because of their caring role. The same research found 42% of carers need more support from the NHS and healthcare professionals and 42% wanted needed greater recognition from the NHS of their needs as a carer. This includes greater flexibility when making appointments, allowing them to balance their own health needs with their caring role. [xx]

What parents and carers told us

Access to healthcare for both carers and those they care for remains a significant concern. Many respondents highlighted the difficulty in accessing timely appointments, particularly for non-urgent but necessary services. There was also a call for better access to healthcare for carers themselves.

In the words of carers

- Getting an appointment for my child is hard enough—forget trying to get one for myself.
- There's no system in place to check on carers' health. We fall through the cracks.
- I would like to come off my antidepressants, but I've just got too much going on.

- My youngest son [an adult] has mental health difficulties. He's been sectioned three times in the last three years. We're his family, you know. We try to advocate for him, but, mental health services do not listen to us. There's no joining up, and it's really upsetting.
- Caring means you give a lot of your time and energy, but to your detriment financially and physically as well. I've hurt my back and it's quite painful these days. I didn't get any manual handling training when I suddenly became a wheelchair pusher, and now I've got long-term pain.
- There is a massive gap for young adult carers. There needs to be better understanding around our particular needs and how unique they are compared to other carers. Whether that it just having young adult meetups or drop ins, or even online sessions - just something - some recognition for the twenty-year-old carers that we do exist.
- Once I aged out from being a young carer, I felt like I was just instantly taken off all of their registers, and I was no longer getting emails to access support, nor was I automatically registered as an adult carer. Being a carer in my twenties meant I had to re-register as an adult carer and actively seek out support, because if I didn't proactively put any of these things in place, the support would just run out. It's like we fall through the cracks.
- I have long-term pain and exhaustion, but I can't take time to deal with it. My child's needs always come first.

Recommendations

For the Integrated Care Board

• Continue to fund and commission carer liaison services within primary care and acute healthcare settings to ensure carers are identified, supported, and connected to appropriate services at key points of contact with the health system.

7. Continuity Of Support For Long-term Carers

Context

Long-term carers are often left without the support they need as caregiving continues for years or decades. This creates a situation where carers experience prolonged stress, isolation, and burnout.

According to Skills for Care data (2023) Bristol's adult social care staff turnover rate was 31%, higher than the national average for England (28%). High turnover is driven by factors including reliance on zero- hours contracts (24% of care staff compared to 3% in the wider population), low wages, and low pay which is commonly less than the National Living Wage. [xxi]

What parents and carers told us

Many respondents, particularly those caring for Disabled family members, talked about the long-term often lifelong caring commitment. The system of support is fragmented along the lines of children and adults, with different entitlements for support for carers and those cared for. Carers have to familiarise themselves with a whole new type of support at transition stages, and their needs often fall within the gaps.

Consistency within children and adult care departments is especially important to families with SEND children, other neurodivergence, and those with neurological diseases.

Furthermore, provision of social care services is fragmented and can change far too often, and carers must start from scratch every time. For example, there is very little continuity in home care, with care workers changing so often, the carers need to explain everything to them all the time. Support needs to be proactive, not reactive.

In the words of carers



This isn't a short-term thing. I've been caring for 12 years and there's no long-term plan or help.

- Support always feels reactive like we're firefighting not like there's a sustainable system in place.
- We need continuity in support, not a revolving door of different people and services every few months.
- We need continuity in support to cope. It's about understanding that the earlier they receive support, the better the outcome will be for that young person. If things are just left, that young person gets worse and worse and worse. Their mental health deteriorates; their behaviours escalate; and the family is obviously impacted by that. By the time that young person is an adult, sometimes they can't be managed anymore, and then they have to be removed from home and then put into some sort of facility when all of this could've been avoided with earlier intervention. Receiving help sooner also saves the council money for the longer term, as putting people in care later on in life also costs money.

Recommendations

For Bristol City Council and all local authorities

- Increase training and pay for care workers to improve retention, job satisfaction, and the continuity of care provided to individuals and families.
- Improve the transition from children to adult services, ensuring it is timely, well-planned, and coordinated to reduce stress for both parents and young people.

8. The Importance of Legal and Advocacy Support

Context

The legal and bureaucratic systems related to caregiving - whether in family court, welfare benefits, employment or healthcare - can be overwhelming and confusing for many carers. Access to legal advice is often not readily available: 70% of the UK population (more than 42 million people), do not have access to a community care legal aid provider. [xxii]

What parents and carers told us

Some respondents expressed the need for better access to legal advice and advocacy services, especially in navigating complex care, family law, employment and financial issues. Carers and parents face multiple systems that can be difficult to navigate, and legal support is often crucial in ensuring their rights are protected.

In the words of carers

- I had to fight for every bit of support. Without legal help, I wouldn't have gotten the care package my child needs.
- We need advocacy—someone on our side who understands the law and the system. We're too exhausted to do it all ourselves.
- I couldn't work when I had my daughter because I had to fight for every bit of support. Going through different support systems, phone calls... It was a job in itself to get the right support for her.
- Navigating benefits and care systems is a nightmare. It feels like they want you to fail,

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Both the school and the council needed to be on board for my daughter to receive the support she needed. Both were resisting. We had to fight for years before she did eventually get the right support. Even then, every year was a battle with giving evidence of how the support was helping her with her autism because the council would have annual review meetings and try to take her one-to-one support away. It's all about money at the end of the day.

Recommendations

For Bristol City Council and all local authorities

• Fund and commission accessible and affordable legal advice for carers, covering areas such as family law, employment issues, financial disputes, care responsibilities, wills, and power of attorney.

Conclusion

Parents and carers are bearing the brunt of the ongoing crisis in early years education, health, and social care. These support systems are under immense pressure due to chronic underfunding, which has severely impacted service provision across key caring economy sectors.

In the absence of sufficient, affordable, and high-quality services, parents and carers are increasingly left with no choice but to take on the majority of care responsibilities at home - often alone and unsupported.

Since the COVID-19 pandemic, the intensity of unpaid care has increased significantly across the UK. This is particularly concerning, as those providing high levels of care are less likely to maintain employment and more likely to experience poverty, ill health, and social isolation. This is detrimental to individuals, to families and to the economy more broadly.

The findings of this report are not new and many of the recommendations have been made before. Indeed, some commitments to parents and carers are included in existing strategies; Bristol City Council's Green and Fair Economic Strategy, for example, includes as a priority: "Address workforce shortages and raise the profile of the caring economy through a collaboration with Value the Caring Economy Alliance and regional partners to explore piloting initiatives to enhance employment conditions, pay and training." This is welcomed but much more is required.

Addressing the needs of parents, carers, those they care for requires meaningful support if it is to enable them to escape poverty, isolation, and ill health, and to access flexible, sustainable employment that accommodates their caring responsibilities.

Outreach efforts must be made to support those with the most hidden and urgent needs. Furthermore, to maximise the impact and efficiency of support, the intersectional - particularly gendered - nature of care and barriers to accessing support, must be recognised and addressed. Embedding this understanding across all strategies and plans will enhance their responsiveness.

There is little new information about the need that can be shared; it is time for a new response.

Next Steps

The Caring Economy Alliance's Commitment to Action

This Bristol Women's Voice report aims to guide future action to ensure that Bristol becomes a more supportive and inclusive city for all families and carers.

As part of the Caring Economy Alliance, Bristol Women's Voice will take the following initial steps in response to the recommendations outlined in this report:

1. Update the Online Directory of Women's Services

We will expand our searchable directory to include comprehensive information for parents and carers. This will feature carer-friendly GP services, peer support groups and activities, and sources of legal advice and information.

2. Collaborate on Employment Standards

We will work with parents and carers to review the Good Employment Charter, propose revisions, and support the development of a new Flexible Working Standard that reflects the realities of caregiving.

3. Support Women's Economic Well-being

In partnership with local specialist agencies, we will develop a series of workshops focused on improving women's financial resilience and economic independence.

4. Promote Carer-Inclusive Workplaces

We will partner with the Women in Business Charter and carers to cocreate training for employers, helping them build more inclusive, supportive environments for staff with caring responsibilities.

Summary of Recommendations

For national government

- **1.Simplify the benefits system** to ensure timely, accessible support without excessive bureaucracy, especially for carers and lowincome families.
- **2.Address the long-term financial impact of caring on women** by introducing measures to compensate for lost pension contributions and income protections.
- 3. Introduce statutory paid care leave.
- 4. Widen the eligibility criteria for the 30 funded hours of childcare to include parents in education and training.

For the West of England Mayoral Combined Authority

- 1.Co-create a region-wide standard for flexible working and caring employment in partnership with carers.
- **2.Review and update the Good Employment Charter** to embed this standard and promote inclusive workplaces for carers and parents.
- **3.Require adherence to the caring employment standard** as a condition for procurement and commissioning.
- 4. Develop training with the Caring Economy Alliance and carers to help employers understand caring roles and responsibilities, fostering a culture where carers are supported rather than overlooked or penalised.

For WECA, Bristol City Council and all local authorities

- 1.Invest in training and career progression for Early Years workers, including funding for backfilling posts to enable staff to pursue qualifications such as Level 3.
- **2.Subsidise wages for low-paid Early Years workers and apprentices**, especially in disadvantaged areas, to improve retention and workforce stability.

For Bristol City Council and all local authorities

- 1. Prioritise carers facing financial hardship in the allocation of the Household Support Fund. This should explicitly include carers of adults and carers of children with SEND (Special Educational Needs and Disabilities).
- **2.Improve access to information about financial support for carers** by simplifying content, ensuring clarity, and producing printed materials to address digital exclusion.
- **3.Commission targeted outreach** to identify and engage carers who may not be accessing existing support.
- **4. Fund carer support organisations** to deliver financial advice and practical assistance tailored to carers' needs.
- **5.Expand access to inclusive services such as after-school clubs** and trusted care activities, particularly for children with SEND and other vulnerable groups.
- **6.Provide tailored financial guidance for parents**, helping them navigate and access available financial support schemes.
- **7.Invest in care services** that provide regular breaks for carers, including both short-term and extended respite options.
- 8. Explicitly recognise the intersectional and gendered nature of care across adult social care and funding strategies.
- 9.Continue and expand funding for local support groups for parents and carers, particularly those with specific caregiving needs
 such as parents of children with SEND, elderly carers, young carers, and those supporting individuals with complex health conditions.
- 10. Increase training and pay for care workers to improve retention, job satisfaction, and the continuity of care provided to individuals and families.
- 11. Improve the transition from children's to adult services, ensuring it is timely, well-planned, and coordinated to reduce stress for both parents and young people.
- 12. Fund and commission accessible and affordable legal advice for carers, covering areas such as family law, employment issues, financial disputes, care responsibilities, wills, and power of attorney.

For the Integrated Care Board

- **1.Develop and deliver training for healthcare providers** to better understand and respond to the mental health needs of carers.
- **2.Expand access to mental health services for carers**, including online counselling and support groups, ensuring ease of access and flexibility.
- 3.Continue to fund and commission carer liaison services within primary care and acute healthcare settings to ensure carers are identified, supported, and connected to appropriate services at key points of contact with the health system.

For all employers (including regional and local authorities)

- **1.Implement mandatory carer support training** for all staff and managers to build an understanding of carers' needs in the workplace.
- **2.Ensure workplace policies are inclusive** of caring responsibilities, creating a proactive and supportive environment for employees who are carers.
- **3.Promote workplace-based childcare facilities** to support working parents and improve work-life balance.
- **4.Offer and actively support flexible working arrangements** to accommodate the needs of parents and carers.

For the Voluntary, Community and Social Enterprise Sector

1.Explore, document, and share good practice in supporting carers to access the services they need, with a focus on removing barriers and improving coordination across sectors

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