Centre for Care

Economic and Social Research Council

Funded by NIHR | National Institute for Health and Care Research

June 2026

Recommendations for Cross-Government Action Plan on Carers

Summary

We recommend the creation of a new social contract to protect and enhance unpaid carers' wellbeing, echoing the calls by the APPG on Carers for a new, cross-government national carers strategy that aligns social care, housing, health, employment and social security to deliver the breadth and depth of support that carers need. Specifically, this strategy should include measures to support:

1. The Strategic Identification and Recognition of Carers
2. Investment in Supporting Carers' Wellbeing
3. Reform of Financial Entitlements and Advice for Carers
4. Strengthening Carers' Employment Rights
5. Tackling Broader Inequities

The rationale

A national carers strategy would make clear that unpaid carers are an integral and valued part of the care ecosystem; without them, the system would collapse.[1] Many carers, far from feeling supported as they give help to loved ones in need, face a triple penalty: deterioration in their own health; financial strain; and isolation, loneliness and a feeling of being cut off from the daily life others take for granted.[2] A national strategy is needed to drive significant improvements at pace, addressing these failings in our current care arrangements. The strategy should be underpinned by a human rights based approach, and raise public awareness of this often invisible and undervalued work. It should also help to encourage joined-up working between different policy domains.

The policy imperative

The direction of the NHS 10-year-plan makes these recommendations increasingly urgent. The NHS is moving towards earlier discharge, virtual wards, hospital-at-home and digital-first care. All of these models assume there is an unpaid carer in the home who can monitor, coordinate, and escalate the needs of the person receiving care. That reliance is mostly left unsaid in current policy documents, but it should not be: if we build services that assume a prominent role for unpaid carers, we must ensure that unpaid care is supported across other policy domains. If we ask carers to do more without building in support, the reforms of the NHS will falter and carers' wellbeing will be compromised.

1. The Strategic Identification and Recognition of Carers

Context and evidence

Across the UK, there are at least 5.8 million unpaid carers (9% of the population - as identified in the Census 2021), but the true figure could be as high as 10.6 million people.[3] This uncertainty arises as many do not recognise themselves as carers, nor are they identified as such by organisations who could help. Carer identification matters, because it is the first step towards well-targeted support and addressing inequalities.[4] Analysis suggests that there is significant under-recording of unpaid carers by the NHS and local authorities - e.g. GP records capture only 10% to 28% of the carers indicated by the 2021 Census.[5] Recent research suggests that long-term condition reviews and annual health checks for people aged 40-74 offer an opportunity to identify carers and to make them aware of the support available[6] - yet as many as 1 million unpaid carers are currently unrecognised by their GP.[7] Nearly 70% of schools have no records of young carers, despite estimates that every classroom has at least one young carer, with a lack of support impacting on their lifetime opportunities, including significant education, health and labour market disadvantages.[8]

Trust is an important step in encouraging carers to self-identify. Emerging research with disabled people who are carers suggests that identification is not always experienced as beneficial or safe. For example, in contexts where welfare eligibility is tightly scrutinised, being recognised as a 'carer' can risk undermining claims to Personal Independence Payments (PIP), leading carers to feel ambivalent about self-identification.[9] There is evidence that the 'hostile environment' policies continue to deter some people from racially minoritised communities from seeking access to public services, regardless of their migration status and rights and entitlements, as they fear they will be treated with suspicion[10]. Empathy is also important, with a need for public services to move away from adversarial processes and actively recognise carers as 'experts by experience' and equal partners in care provision.[11]

We recommend:

- **National awareness-raising of what it means to be a carer, and the support available, is also needed to help carers to self-identify**, particularly amongst underserved populations. This is a critical first step for effectively targeting support and reducing inequalities, and is particularly important in the period before the 2031 Census is underway.
- **Proactive identification of carers, and support to help carers self-identify**: Public services, including social care, the NHS, Job Centre Plus and local authorities, must adopt a strategic and systematic approach to proactively identify unpaid carers and capture this on their records. For example, critical moments for identification include by GPs at key or repeat appointments, by hospitals at discharge, first contact with social care services, and in schools where children attend who have care needs or are young carers.
- **Schools and services should offer young carers and young adult carers an opportunity to select a "don't know" option** (with then a follow-up conversation) in addition to binary 'yes/no' answers about whether they care, as well as transparency about what will happen to this information.[12]
- **The development of education, information, and training for a range of public service professionals.** We need a workforce across public services – not limited to the care sector – that understands who carers are and how to support them, including better signposting, referral, and empathy.
- **A commitment to a 'firewall' which means that personal data held by essential health and social care services will not be shared with the Home Office for immigration enforcement purposes** to enhance trust and encourage underserved communities to self-identify as carers and access support. [13]
- **Recognising carers as partners in care provision**: Carers are a vital part of the social care workforce, but their expertise and skills are often ignored or dismissed. Building on the recent 'Review of CQC Regulation 9A: visiting and accompanying in care homes, hospitals and hospices', There must be a move away from systems and processes that penalise carers for asserting themselves and advocating for the person they care for, and toward processes that recognise carers as experts by experience and value their input.
- **The Census 2031 should continue to include the question about whether someone is an unpaid carer, and the intensity of their caregiving**. This is an invaluable data source for researchers and policymakers to analyse the population characteristics of unpaid carers across time (comparing the 2001, 2011, and 2021 results) and to investigate inequalities which could not be robustly examined with a smaller dataset.

2. Investment in Supporting Carers' Health and Wellbeing

Context and evidence:

The UK has historically been seen as a leader within the international carers movement; however, it is clearly evident that we are falling behind other nations in ensuring that carers can enjoy a decent quality of life.[14] Availability of good quality, affordable social care is fundamental both for unpaid carers and the person they care for. When appropriate and trusted social care is in short supply, this has consequences for the intensity of care that carers undertake, their ability to stay in paid employment or to take breaks from caring to focus on their own wellbeing.[15]

There is increasing evidence that caring is a social determinant of health[16], and should therefore be included in national and local programmes to tackle health inequalities. Caring responsibilities can have a significant impact on physical and emotional wellbeing, particularly when people care for extended periods of time or at a high intensity.[17] Over time these impacts can become life-threatening, with as many as 40% of unpaid carers reporting thoughts of suicide and at least one homicide or homicide-suicide each month in the UK perpetrated by an unpaid carer.[18] Experiencing high levels of distress, burn-out, or not having time to prioritise their own health is likely to mean that carers have a greater need for NHS resources. Our work shows many carers are providing high-intensity care while their own health is under strain, and that lack of breaks or respite care makes arrangements fragile.[19] This is a particularly acute challenge for the 27.5% of disabled people who self identify as unpaid carers in England[20], who often provide high-intensity care while managing their own support needs, highlighting the limitations in current policy frameworks that assume a clear distinction between carer and cared for. The issue is not solely that care has the potential to harm health, but that unpaid care is relied upon in ways that ignore carers' pre-existing health needs. Evidence indicates carers need regular, affordable and high-quality respite, help to attend their own appointments, and rapid access to high-quality and quick substitute care when something changes.[21]

Whilst policy includes provision to ensure carers are supported, in practice the delivery of this support is uneven. The Care Act 2014 entitles carers to an assessment of their own needs and requires local authorities to provide support for any identified needs. The assessment should cover how caring affects a person's life, including their physical, mental and emotional needs. This includes: their role as a carer and how they feel about this; whether they're able and willing to continue as a carer; their health; employment; what they enjoy doing in their free time; and planning for emergencies. Although the Care Act emphasises the importance of wellbeing, in practice its implementation has been hindered by severe underfunding of adult social care (and local government more broadly)[22] and there is growing evidence that carers find it increasingly challenging to access publicly funded support even if they have an assessment. A network of local carers centres delivers support across the UK and are often commissioned to deliver specific services by local government, including Carer's Assessments. However, they almost always operate under severe resource constraints, and are heavily reliant on short-term and grant funding. As a reflection of this context, in 2024 only 23% of carers reported having received an assessment and of those 42% say their local authority did not provide any support following the assessment[23]. Over the past decade, the number of carers receiving direct support from local authorities has fallen; in 2023/24, just 308,000 carers did so.[24] This stands in stark contrast to the 1.4 million people claiming Carer's Allowance at that time. Carer's Allowance claimants must provide at least 35 hours of care per week to someone - and might reasonably therefore be thought to be in need of support from their local authority. In the context of austerity, there simply may not be appropriate support available to meet their needs and it is not easy for carers to invoke their legal rights.

We recommend:

- **Caring is formally recognised as a social determinant of health** and integrated into national and local programmes designed to address health inequalities.
- **Long-term, sustainable investment in local government** to resolve the crisis in social care access, both for people with care and support needs and unpaid carers. This funding is essential to ensure that carers have a choice about caring, that they receive the holistic support they are legally entitled to, and that local authorities can prioritise investment in preventative support.
- **A preventative approach that helps carers maintain their own health, relationships, financial security and employment, and reduces the number of carers who reach crisis point.** This includes a right to a break from caring. There needs to be a strong emphasis on personalisation, creativity and flexibility to meet carers' diverse needs and preferences. The Scottish Government is currently consulting on the introduction of a right to personalised short breaks for unpaid carers as part of the Care Reform (Scotland) Act 2025.
- **For carers already experiencing physical or mental health difficulties, the government must ensure access to timely and appropriate support**, as well as opportunities to safely relinquish care when it is no longer sustainable.
- **Support that addresses carers health and wellbeing should be available across the caregiving journey** (including the post-caregiving phase) and at key transitions points (which are complex and include but are not limited to moving into and out of the caregiving role).[25]

3. Reform of Financial Entitlements and Advice for Carers

Context and evidence:

Many carers worry about day-to-day costs and experience a cumulative long-term impact on their earning potential, pensions and savings.[26] This cumulative disadvantage poses the greatest risks to people already facing financial insecurity. Centre for Care research[27] finds that the impact is primarily felt once in or nearing retirement, when the reality of inadequate private pensions savings causes stress, but midlife carers feel there is little they can do to remedy their situation. This highlights that carers rarely are able to consider the longer-term financial consequences when making a 'decision' about work and care; often carers make decisions quickly and under considerable pressure due to the crisis nature of their situation.

There is limited statutory support to adequately address these costs. Centre for Care research estimates the 'caring income penalty' by quantifying how unpaid care impacts people's income; it finds that unpaid carers providing 50+ hours of care per week saw their personal income fall on average by £162 per month, with losses peaking at £192 per month after four years.[28] Younger unpaid carers (under 25 years old) face the steepest penalty - losing up to £502 each month.

Despite this steep income penalty, Carer's Allowance is the lowest earnings replacement benefit. It is no longer fit for purpose, having barely changed since being introduced 50 years ago, while the profile and prevalence of carers and the world of paid work are dramatically different. The original intended recipients of Carer's Allowance were single daughters cohabiting with and caring for their parents (and as a result not in work) - a situation that is not representative of today's population of unpaid carers. Currently Carer's Allowance is also limited to people who are caring for one person for more than 35 hours a week, with no additional payments made to those caring for more than one person and excluding those caring for two or more people but adding up to 35 hours in total. Today in England and Wales:

- 57% of unpaid carers are married and 41% are men.
- More than half of unpaid carers are in paid employment at the same time (Centre for Care Unpaid Care Dashboard using Census Data).[29]
- 'Distance caring' is a global phenomenon[30] and an issue in the UK[31] as families are dispersed, including across international borders.[32]
- Data from the 2022/3 Family Resource Survey indicates that of all unpaid carers surveyed, half provided care to someone living outside their household, with this most likely to be partners or children, whereas only 8% were caring for parents with whom they lived with.
- Ten percent of those surveyed were also caring for more than one person at a time.[33]

Carer's Allowance is only one part of the picture for carers. Carers encounter further complexity and poor treatment in the system when they apply for other benefits themselves (e.g. the Carer Element of Universal Credit, or Personal Independence Payment [PIP]), or if they are heavily involved in the process of claiming a benefit for the person they care for (e.g. PIP, Attendance Allowance, child Disability Living Allowance). Centre for Care research finds that carers' abilities to claim their entitlements are undermined by cultural issues at DWP including high staff turnover, a lack of understanding about their needs, limited accountability and one-sided conditionality. Interactions with the DWP cause a high degree of stress and anxiety for carers.[34]

The welfare advice sector is crucial for many carers being able to access their benefits entitlements, however not all welfare rights services offer the same level of advice and expertise - leading to geographical variation, for example, in access to advice on appeals. Worryingly, some carers services are reticent to advise on Universal Credit claims, because it is so complex and there are so many decisions which need challenging[35].

We recommend:

- **A comprehensive review of welfare entitlements for carers.** Policy should reduce, not reproduce, the financial penalties of caring — through better-calibrated allowances, recognition of intensity/hours, and protection for pension rights.
- **Review the rates of carers' benefits** to ensure that they provide a minimally acceptable standard of living, taking into consideration the importance of recognising their contribution to society, the cost of living, the additional costs of caring and the income penalty experienced by carers over their lifetime.
- **Ensure that that the needs and experiences of carers are central to the Timms Review,** which must consider the impact of any changes to PIP on carers. 14.5% of Carer's Allowance claimants in 2024 also claimed PIP.36**Carer's Allowance must be reviewed and reformed:**
  - ◊ **To be modernised** with a full review of both the payment amount and eligibility criteria, ensuring it genuinely reflects the value of care and the costs incurred by carers. The Allowance should be updated to reflect 21st-century caring relationships and to enable carers to participate in the modern labour market.
  - ◊ **To be more flexible** to reflect the reality of people's caring relationships, for instance, by allowing payment to be shared among multiple carers; offering higher payments to those caring for multiple people; and allowing a carer to meet the 35 hours weekly caring condition by adding up the care they provide to more than one person.
  - ◊ **To remove the current 'cliff-edge' earnings threshold** and either significantly increase or abolish the earnings threshold.
  - ◊ **To prevent the massive debts caused by accidental overpayments,** the government should automate earnings adjustments using real-time data (similar to Universal Credit).
- **Fully implement the recommendations of the Independent Review of Carer's Allowance Overpayments led by Liz Sayce OBE,** including a commitment to rapidly identifying cases of overpayments caused by systemic issues so that debts can be written off and/or repaid to carers. An official apology to the carers affected, as well as compensation for those who were wrongly prosecuted by DWP should also be explored, in recognition of the trauma caused.
- **Reform must also address interaction between benefits, not just improve Carer's Allowance in isolation.** The 'overlapping benefits rule' means:
  - ◊ Any increase to the value of Carer's Allowance will be lost by carers claiming more than one income-replacement benefit.
  - ◊ Carers who receive a State Pension no longer receive a Carer's Allowance payment, despite still incurring costs associated with caring.
  - ◊ If a carer supports someone in receipt of the Severe Disability Premium in their means-tested benefits, then claiming Carer's Allowance (or the Carer Element of Universal Credit) means that they would lose this. Interactions between benefits can lead to a domino effect (since there are implications for Pension Credit, and therefore associated benefits including Winter Fuel Payment, the TV Licence council tax, and Housing Benefit), meaning they lose a significant sum - this usually leads the carer to decide not to claim for themselves.
- **Review and simplify the interactions between Carer's Allowance and Universal Credit:** this should be with the aims of i) making it clearer to carers whether it is more beneficial for them to claim Carer's Allowance, Universal Credit, or both; ii) making their communications with DWP more straightforward; and iii) preventing overpayments which arise from this complex interaction (echoing recommendations from the Sayce review).
- **Develop a publicly available policy setting out how DWP will safeguard the wellbeing of vulnerable claimants (including carers),** including a commitment to cultural change so that their wellbeing is centred in the design, planning and implementation of policy. Specialist training for DWP staff to understand caring would foster greater empathy and understanding of carers' rights.

- **Remove punitive measures that fail to recognise the reality of unpaid carers' lives,** such as refusing Carer's Allowance to those in full-time higher education,[37] the withdrawal of Carer's Allowance after 28 days if the care recipient is hospitalised, the fact that Carer's Allowance cannot be fast-tracked under Special Rules for people with terminal illness (unlike disability benefits), and the cliff-edge of benefits and support when the person being cared for dies. Align with recent policy developments in Scotland where the Carer Support Payment continues for 12 weeks after the death of the person being cared for dies. Households carers living in this situation face significant and immediate financial changes: losing Carer's Allowance, PIP and access to a Motability vehicle. A grace period or lump sum could address this financial shock at a time of emotional distress.
- **Introduce a statutory duty to provide social welfare advice,** which is available to all who need it and free at the point of delivery, as called for by the National Association of Welfare Rights Advisers (NAWRA). Carers' ability to claim their entitlements hinges on an overstretched and underfunded advice sector, with variations in access to different levels of support geographically. A statutory duty would address inequity and unsustainability in current provision.
- **Raise awareness of Carer's Credit which protects carers' state pension rights** by ensuring there are no gaps in their National Insurance record. However, it has a low uptake, particularly among those who are not eligible for Carer's Allowance.
- **Introduce policy interventions which take a life-course approach:**
  - ◊ Younger carers would benefit most from early saving support, affordable and secure housing and low-cost travel schemes.
  - ◊ Mid- and later-life carers need access to clear pension information and financial protection from care-related employment breaks.
  - ◊ Workplace pension communications should explicitly highlight the long term effects of reducing hours to care.

We recommend the creation of a new social contract to protect and enhance unpaid carers' wellbeing, echoing the calls by the APPG on Carers for a new, cross-government national carers strategy that aligns social care, housing, health, employment and social security to deliver the breadth and depth of support that carers need.

4. Strengthening Carers' Employment Rights

Context and evidence:

Many carers find that juggling paid work and caring responsibilities is just too difficult. (We acknowledge that it is not possible for all unpaid carers to be in paid employment; for some, the demands of caring are simply too high or unpredictable). Without proper support, carers are often forced to reduce their hours, move into lower-paid or more flexible but often less secure work, or leave employment entirely - every day, 600 people give up paid work to care.[38] This can mean:

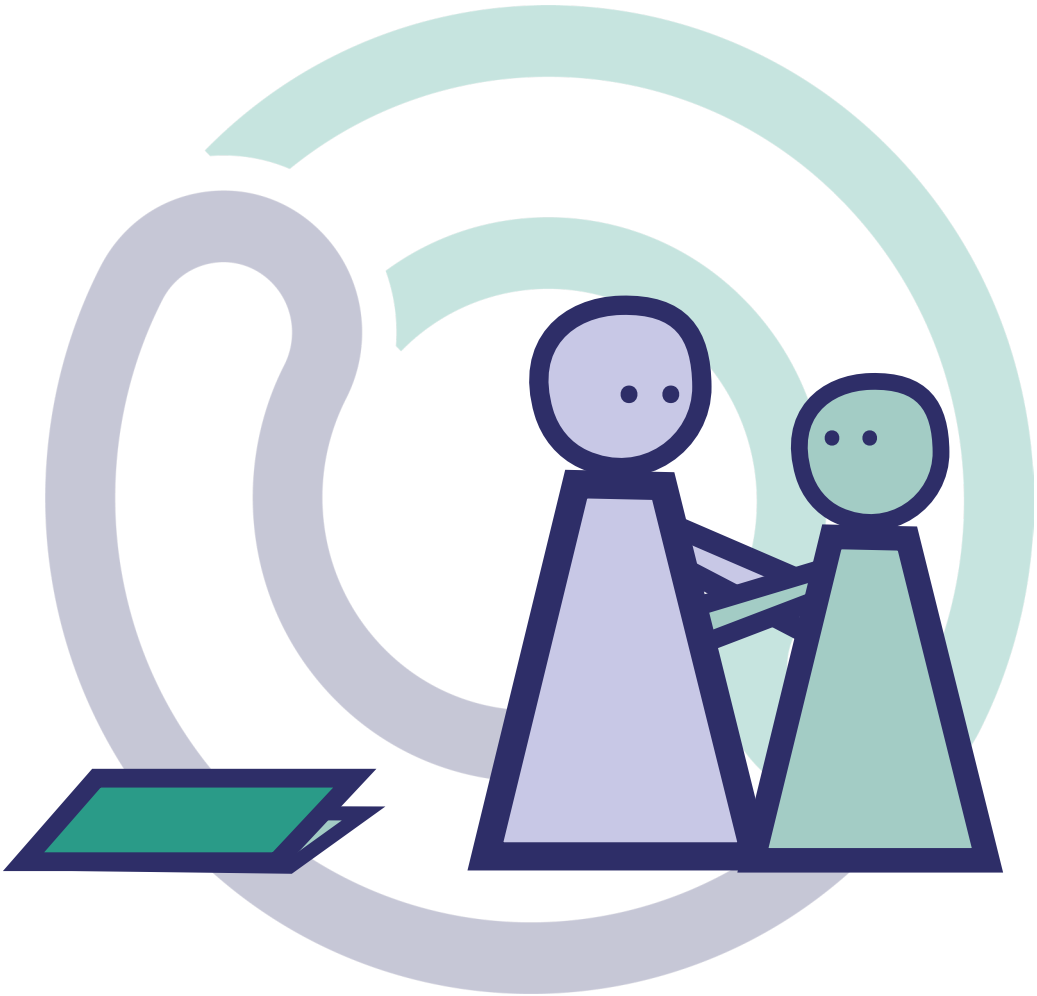
- Significant reductions in income[39], whilst often facing additional costs related to caring.
- A loss of the sense of identity and the social connections[40] that (good) employment can bring. This can lead to poor mental health outcomes, including increased risk of suicidal thoughts and behaviours[41].
- Difficulties returning to the labour market after an extended absence.[42]
- Long term financial strain[43], with reduced pension contributions and assets.

Carer's leave supports carers to better manage both roles. The Carer's Leave Act 2023 gives unpaid carers a statutory right to leave, but it is estimated that less than 15% of carers in paid employment have taken this leave.[44] For many carers - particularly those in low-income or insecure jobs - unpaid leave is not a viable option.[45] If carers have to bear the cost of taking leave by losing pay, then it is likely that women and those on lower incomes will face significant barriers to using it. If leave is not paid, then employees may use their sick leave or annual leave, with detrimental consequences for their overall wellbeing.

Without financial support, taking time off can result in significant hardship, even leading to poverty or job loss. International evidence shows that paid carer's leave can significantly boost uptake, helping carers to remain in work[46], and to manage essential expenses during times of crisis. It transforms Carer's Leave from a theoretical right into a practical lifeline.

We recommend:

- **The introduction of statutory paid leave:** The government should use legislation like the Employment Rights Bill to introduce a statutory right to paid carer's leave. Implementing paid leave will help carers balance their responsibilities without falling into financial hardship, while simultaneously boosting employer retention, reducing unplanned absences, and improving overall productivity.
- **Support for carers who need to take a longer-term break from employment:** Explore policy options to provide employees with the right to take a longer period of leave so carers do not fall out of the labour market when they have particularly complex and intense periods of unpaid care, and provide supported pathways back into work.
- **Protect carers from workplace discrimination:** Making caring a protected characteristic by updating the Equality Act 2010 to strengthen carers' rights to protection from discrimination and harassment in the workplace.
- **Create tailored employment support for carers at the end of their caring journeys** who need help to re-enter the labour market.[47]



5. Tackling and Understanding Broader Inequities

Context and evidence:

Caring often amplifies existing disadvantages. When someone takes on a caring role, any systemic inequities they already face - whether financial, health related, or structural — are magnified. The caring population is diverse, and inequities exist both with regard to who cares, and who experiences the greatest disadvantage as a result of caring. Women are more likely to provide care, to have provided care for longer and to care more intensively than men.[48] On average, women can expect to take on caring responsibilities over a decade earlier than men. As well as the day-to-day impact on their finances, this has long-term consequences for their employment opportunities, financial security and pensions. Women face a 30% relative income penalty in individual income for high-intensity caring (more than 50 hours per week of care), compared to 25% for men.[49] Caring is a major driver of the gender pension gap in the UK; by the time women reach 55, their private pension pots are on average 35% less than men's.[50] Furthermore, marginalized groups – including carers, from racially minoritised and Gypsy, Romany and Traveller communities, young carers, and LGBTQ+ communities – face compounded disadvantages and significantly worse outcomes.

These inequalities can be better understood through the creation and use of data on unpaid carers. Major gaps in data currently collected (in the Census, Understanding Society and the Survey of Adult Carers in England) include the level of unmet need among carers, their use and experience of services and the impact of these, and what forms of support carers find most useful. Attention must be paid to reaching a more diverse and representative sample of unpaid carers, including those who are not known to their Local Authority. The Centre for Care team has been working with DHSC to design and deliver a pilot of a new survey of unpaid carers to significantly develop understanding of this population for several years (as promised - Action 5.3 - in the Government's Carers Action Plan 2018-20). Currently it is very challenging to know how effective different kinds of services and supports are in helping carers avoid the negative health, financial and social isolation consequences frequently seen among the carer population, particularly under represented groups e.g. those new to caring, self funders, caring at distance, caring intensively or over long periods. The pilot survey will capture data from carers not in contact with their local authorities, addressing challenges that accompany the Survey of Adult Carers in England.

In addition, there is limited evidence both on who has unmet needs and why this is. It is highly likely that people from marginalised groups who experience multiple disadvantages and may struggle to access a range of public services, including adult social care, are under represented in the data currently collected. Evidence shows high levels of mistrust among some communities about sharing data with public agencies (as described in Section 1 in relation to 'hostile environment' policies). The 'social licence' for collecting and analysing data is fragile[51]; public trust needs to be earned.

Triangulation and synthesis of the findings from both large-scale surveys and qualitative insights is essential. Often, survey data are collected using categories derived from those used in the Census. While this has some benefits, it can be problematic. Aggregating ethnic categories, as public agencies often do, cannot capture important variation between and within groups whose lived experience needs to inform how personal data is recorded.[52]

In addition to developing understanding of inequities amongst the caring population, policy should not unintentionally exacerbate existing inequalities and disadvantages faced by carers. For instance, the shift toward 'digital-first' public services often disadvantages carers who lack digital confidence or the financial resources for devices and internet access.[53] Centre for Care research highlighted issues of trust in online services and a fear of 'scams' as barriers to carers' digital inclusion.[54] Preferences and around technology use, and experience with technologies are shaped by levels of trust - e.g., that the technology will function, and that data will be used and stored appropriately. Poverty levels, age, ethnicity, and rurality all impact likelihood that individuals are digitally excluded - research shows that individuals classified as 'limited users' of online technology are four times more likely to come from low-income households, 1.5 times more likely to belong to Black, Asian, and minority ethnic groups, and eight times more likely to be over the age of 65.[55]

We recommend:

- **Address the gender care gap**: Policies must acknowledge and mitigate the disproportionate impact caring has on women, who often care more intensively and earlier in life. Initiatives like paid carer's leave can actively help reduce the gender pension gap and prevent later-life poverty.
- **Recognise the impact of intersectional disadvantage**: Targeted support must be provided for marginalised or seldom heard communities (including racially minoritised carers, Gypsy, Roma and Traveller carers, young carers, disabled, and LGBTQ+ carers) who receive less support and have worse outcomes.
- **Use data and evidence to understand the inequalities and inequities within the unpaid carer population**: National policy and legislative change have to be coupled with more effective local planning to provide the bespoke services and supports where carers live and provide care. Local areas - councils, ICBs and local carer organisations – need to understand their carer population – both now and likely trends into the future - clearly, so they can target support. Better data and reporting as well as integrated data infrastructures that promote the synthesis of multiple forms of data (both structured and unstructured) will facilitate data-driven policy and practice.

ENDNOTES

[1] Petrillo, M., Zhang, J., and Bennett, M.R. (2024) Valuing Carers 2021/2022: the value of unpaid care in the UK. London: Carers UK

[2] Keating, N., McGregor, J.A. and Yeandle, S. (2021) Sustainable care: theorising the wellbeing of caregivers to older persons. International Journal of Care and Caring, 5(4). pp. 611-30.

Bennett M.R., Zhang Y. and Yeandle S. (2020) CARING and COVID-19 Loneliness and use of services

Bennett, M, Zhang, Y & Yeandle, S (2020). Caring & COVID-19: Hunger and mental wellbeing

Bennett, M, Zhang, Y & Yeandle, S (2020). Caring and COVID-19: Financial Wellbeing

[3] Carers UK (2022) State of Caring 2022. A snapshot of unpaid care in the UK. November 2022.

[4] Vicario, S. (2023), "Am I a carer?" Why self- and social identification of carers are becoming unavoidable topics.

[5] Health Foundation (2023), Can you tell we care? Identifying unpaid carers using local authority and GP records.

[6] Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, et al. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. Health Soc Care Deliv Res 2026;14(6). https://doi.org/10.3310/GJKR4724

[7] Paddison, C. and Sherlaw-Johnson, C. (2025). How good are general practices in England at recording who is an unpaid carer?

[8] Leadbitter, H; Morris, D; Cartlidge, K.; Samways, E.; Blackmore, C. and Fry, L. (2025). My Time- Young Carers. Unseen Sacrifices: understanding the educational disadvantages faced by young carers.

[9] Grosset, C. (2025). Overview of welfare reforms

[10] Lingham, J.T. and Kilkey, M. (2025). Migration and the Right to Care: Summary of a research study on migration and care. University of Sheffield: Centre for Care.

[11] Ribenfors, F., Smith, M., Runswick-Cole, K. and Ryan, S. (2025) 'Kindness and curious kinships in the lives of family carers of adults with learning disabilities', International Journal of Care and Caring

[12] Alexander, C. (2025). Briefing: Young adult carers and the 'don't know' option.

[13] Liberty (2018) Care Don't Share. Hostile environment data-sharing: why we need a firewall between essential public services and immigration enforcement

[14] Yeandle, S. (2016), Caring for our carers: An international perspective on policy developments in the UK. Juncture, 23: 57-62. https://doi-org.sheffield.idm.oclc.org/10.1111/j.2050-5876.2016.00896.x

Brimblecombe, N., Fernandez, J. L., Knapp, M., Rehill, A., & Wittenberg, R. (2018). Review of the international evidence on support for unpaid carers. Journal of Long-Term Care, (September), 25-40. Zhang, W., Rand, S., Milne, A., Collins, G., & Silarova, B. (2022). The quality of life of older carers and the people they support: an international scoping review. Health & social care in the community, 30(6), e3342- e3353

[15] Overton, L. & Watkins, M. (forthcoming) Understanding the lived experience of unpaid caregiving and risks to financial wellbeing. [Journal of Social Policy]

[16] Public Health England (2021) https://assets.publishing.service.gov.uk/media/60547266d3bf7f2f14694965/Caring_as_a_social_determinant_re port.pdf

[17] Zhang, Y. and Bennett, M. R. (2024). Insights into Informal Caregivers' Wellbeing: A Longitudinal Analysis of Care Intensity, Care Location, and Care Relationship. The Journals of Gerontology: Series B, Psychological and Social Sciences. 79(2): 1-12.

[18] O'Dwyer, S.T., Janssens, A., Sansom, A., Biddle, L., Mars, B., Slater, T., Moran, P., Stallard, P., Melluish, J., Reakes, L., Walker, A., Andrewartha, C. & Hastings, R.P. (2021). Suicidality in family caregivers of people with long-term illnesses and disabilities: A scoping review. Comprehensive Psychiatry, 110,152261.

O'Dwyer, S.T., Sansom, A., Mars, B., Reakes, L., Andrewartha, C., Melluish, J., Walker, A., Biddle, L., Slater, T., Burrows, D., Hastings, R.P., Moran, P., Stallard, P. & Janssens, A. (2025). Suicidal thoughts and behaviors in parents caring for children with disabilities and long-term illnesses. Archives of Suicide Research, 29(2), 468-485.

O'Dwyer, S.T., Bishop, C., Gimson, R., Melendez-Torres, G.J., Stevens, D. & Hardy, L. (2025). From caring to killing: A typology of homicides and homicide-suicides perpetrated by caregivers. Social Sciences, 14(6), 376.

[19] Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, et al. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. Health Soc Care Deliv Res 2026;14(6). https://doi.org/10.3310/GJKR4724

[20] ONS. (2023). Unpaid care and protected characteristics, England and Wales: Census 2021

[21] Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, et al. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. Health Soc Care Deliv Res 2026;14(6). https://doi.org/10.3310/GJKR4724

[22] Needham, C., & Burn, E. (2025). 'Law but not law': explaining unenacted policy as a type of policy failure. *Policy & Politics*, 53(2), 273-95.

[23] Carers UK. (2025). State of Caring: The impact of caring on carers' mental health and the need for support from social care services.

[24] King's Fund (2025) Social care 360: workforce and carers. Available at: https://www.kingsfund.org.uk/insight-and-analysis/long-reads/social-care-360-workforce-carers#9.-unpaid carers

[25] Pelge, H., & Needham, C. (2025). Understanding the lived experiences of working-age disabled people in England and their care-related transitions through the framework of the convoy model. International Journal of Sociology and Social Policy, 1-15.

[26] Watkins, M., & Overton, L. (2024). The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults. Ageing & Society, 1-28.

[27] Overton, L. & Watkins, M. (forthcoming) Understanding the lived experience of unpaid caregiving and risks to financial wellbeing. [Journal of Social Policy]; Watkins, M. & Overton, L. (2025) The lifecourse costs of caring.https://centreforcare.ac.uk/commentary/2025/12/the-life-course-costs-of-caring-understanding-unpaid carers-financial-wellbeing-over-time/

[28] Petrillo, M., Ibarra, D. V., Rahal, C., Zhang, Y., Pryce, G., & Bennett, M. R. (2024). Estimating the Cost of Informal Care with a Novel Two-Stage Approach to Individual Synthetic Control. arXiv preprint arXiv:2411.10314.

[29] See also Petrillo, M.; Bennett, M. and Pryce, G. (2023). Cycles of caring: transitions in and out of unpaid care.

[30] Bei, E., Morrison, V., Zarzycki, M., & Vilchinsky, N. (2023). Barriers, facilitators, and motives to provide distance care, and the consequences for distance caregivers: A mixed-methods systematic review. Social Science & Medicine, 321, 115782.

[31] White, C., Wray, J., & Whitfield, C. (2020). 'A fifty mile round trip to change a lightbulb': An exploratory study of carers' experiences of providing help, care and support to families and friends from a distance. Health & Social Care in the Community, 28(5), 1632-1642.

[32] Hall, K. and Kilkey, M. (2025) 'Care within and across borders: Introducing a transnational convoy of care', International Journal of Care and Caring (published online ahead of print 2025) https://doi.org/10.1332/23978821Y2025D000000118

[33] DWP. (2025). Family Resources Survey: financial year 2022 to 2023. Available at: https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2022-to-2023/family resources-survey-financial-year-2022-to-2023#care-1

[34] https://centreforcare.ac.uk/research-groups/inequalities-in-care/carers-allowance-understanding-complexity and-inflexibility/

[35] See Carer's Allowance: Understanding complexity and inflexibility

[36] Runswick-Cole, K., Ryan, S., Smith, M., Ward, M. and Grosset, C. (2026) '"Well, I Am Now Looking after This Bloody Rabbit!": Re-Storying Care in the Lives of People with Learning Disabilities', Scandinavian Journal of Disability Research, 28(1), pp. 16–27. https://doi.org/10.16993/sjdr.1303

[37] Carers Trust (2024). 19,000 young adult carers could be missing out on vital support during studies because of Carer's Allowance rule.

[38] Carers UK. (2019). Juggling work and unpaid care: A growing issue

[39] Petrillo, M., Ibarra, D. V., Rahal, C., Zhang, Y., Pryce, G., & Bennett, M. R. (2024). Estimating the Cost of Informal Care with a Novel Two-Stage Approach to Individual Synthetic Control. arXiv preprint arXiv:2411.10314.

Watkins M, Overton L. The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults. *Ageing and Society*.

[40] Keating, N., McGregor, J.A. and Yeandle, S. (2021) Sustainable care : theorising the wellbeing of caregivers to older persons. International Journal of Care and Caring, 5 (4). pp. 611-30. ISSN 2397-8821

[41] O'Dwyer et al. (2021). Suicidality in family caregivers of people with long-term illnesses and disabilities: A scoping review. Comprehensive Psychiatry, 110, 152261.

[42] Age UK and Carers UK. (2016). Walking the tightrope: The challenges of combining work and care in later life

[43] Watkins M, Overton L. The cost of caring: a scoping review of qualitative evidence on the financial wellbeing implications of unpaid care to older adults. *Ageing and Society*.

[44] Carers UK. (2024). State of Caring 2024.

[45] Hamblin, K.; Heyes, J. and Fast, J. (2025). Combining Work and Care: Carer Leave and Related Employment Policies in International Context

[46] Niimi, Y. (2021). Juggling paid work and elderly care provision in Japan: Does a flexible work environment help family caregivers cope? *Journal of the Japanese and International Economies*, 62, 101171.

Saad-Lessler, J. (2020). How does paid family leave affect unpaid care providers? *The Journal of the Economics of Ageing*, 17, 100265.

[47] Baxter, S., Cullingworth, J., Whitworth, A., Runswick-Cole, K., & Clowes, M. (2024). Understanding interventions and outcomes in supported employment and individual placement support: A qualitative evidence synthesis. *Disability and health journal*, 17(2), 101579.

[48] Zhang, Y. & Bennett, M. (2019) Will I care? The likelihood of being a carer in adult life, Carers UK

[49] Petrillo, M., Valdenegro, D., Rahal, C., Zhang, Y., Pryce, G., & Bennett, M. R. (2024). Estimating the cost of informal care with a novel two-stage approach to individual synthetic control. arXiv preprint arXiv:2411.10314.

[50] Department for Work and Pensions (2024). The gender pensions gap in private pensions. Accessed: 2025- 899 04-25.

[51] Martin G, Mathur R, Naqvi H. How can we make better use of ethnicity data to improve healthcare services? BMJ 2023; 380 :p744 doi:10.1136/bmj.p744

[52] Martin G, Mathur R, Naqvi H. How can we make better use of ethnicity data to improve healthcare services? BMJ 2023; 380 :p744 doi:10.1136/bmj.p744

[53] Hamblin, K. and Black, R. (2023). Digital exclusion and unpaid carers in South Yorkshire, Centre for Care Research Report, CIRCLE, Sheffield: University of Sheffield.

Roussaki, A.; Sbaffi, L.; Zamani, E.D.; Hamblin, K. and Black, R. (2024). Digital Exclusion and Unpaid Carers. Centre for Care Research Report.

Hamblin, K. and Black, R. (2023). Digital exclusion and unpaid carers in South Yorkshire, Centre for Care Research Report, CIRCLE, Sheffield: University of Sheffield.

Roussaki, A.; Sbaffi, L.; Zamani, E.D.; Hamblin, K. and Black, R. (2024). Digital Exclusion and Unpaid Carers. Centre for Care Research Report.

[54] Hamblin, K., Black, R., 2024. Digital exclusion and unpaid carers in South Yorkshire. https://centreforcare.ac.uk/wp-content/uploads/2023/05/Digital-exclusion-and-unpaid-carers-in-South Yorkshire-1.pdf

[55] Romanowski, H., Lally, C. 2024. Digital disengagement and impacts on exclusion, https://researchbriefings.files.parliament.uk/documents/POST-PN-0725/POST-PN-0725.pdf

Authors:

- University of Sheffield: Professor Kate Hamblin, Professor Katherine Runswick-Cole, Charlie Grosset, Professor Nathan Hughes, Becky Driscoll
- University of Birmingham: Dr Siobhan O'Dwyer, Professor Matt Bennett, Dr Louise Overton.

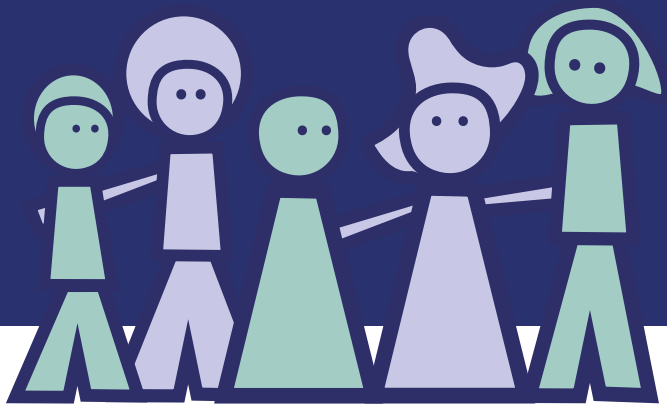
Our recommendations are based on the following projects/ programmes/ centres:

- National Institute for Health Research Applied Research Collaboration South West Peninsula.
- 'Sustainable Care: connecting people and systems' programme (ESRC, 2017-2021).
- Suicidal ideation, homicidal ideation, and self-harm in parent carers (NIHR, 2021-3).
- Tired of spinning plates: an exploration of the mental health experiences of adults and/ or older carers of adults with learning disabilities (National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme, 2021-2024).
- Centre for Care (ESRC/ NIHR, 2021-2026)
- Disabled Carers: Generating New Understandings of Care Provision and Practices from A Critical Disability Studies Perspective (ESRC, 2023-6).

Acknowledgements

©The authors and CIRCLE, The University of Sheffield, June 2026

The Centre for Care is funded by the Economic and Social Research Council (ESRC), award ES/ W002302/1, with contribution from the National Institute for Health and Care Research (NIHR) (Department of Health and Social Care). The views expressed are those of the author(s) and not necessarily those of the ESRC, UKRI, NHS, the NIHR or the Department of Health and Social Care.



Centre for Care

CONTACT

Please get in touch if you would like to know more, or to work with us on related issues, by contacting our support team: centreforcare@sheffield.ac.uk

Website: centreforcare.ac.uk
LinkedIn: @Centre for care