Written evidence submitted by Centre for Care – University of Sheffield (ASC0089)

House of Commons Health and Social Care Select Committee
Centre for Care submission to inquiry: Adult Social Care Reform: The Cost of Inaction

This submission draws on research carried out by academics at the ESRC-funded Centre for Care at the Universities of Sheffield, Birmingham and the London School of Hygiene and Tropical Medicine.

We would like to highlight that Centre for Care Co-Investigator Professor Matt Bennett has also submitted evidence to this inquiry (together with Professor Jon Glasby), on the urgent need for adult social care reform and the economic value of unpaid care in the UK.

1). How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

1.1 When it was last in power, the Labour government's *Building the National Care Service* white paper stated:

> *"The current care and support system is no longer sufficient. It cannot meet our needs, nor match our aspirations. If left unchanged, it would not cope with the extra demand in years to come."*[1]

In the 15 years since then, the system has been largely unchanged, despite three potential moments of transformation. This has had significant impact on people with care and support needs, unpaid carers, as well as providers and commissioners of care, and the NHS:

i). The Care Act 2014

1.2 The Care Act 2014 attempted a wholesale reform of social care but it has had limited success in changing practice and improving outcomes for people who draw on care and support.[2] The wide-ranging aims of the Act focused on:

- a shift from local authorities providing services to supporting wellbeing
- facilitating choice and control
- reducing, delaying or preventing future need and demand for services.

1.3 Implementation required stakeholder engagement at multiple levels: the macro (national), meso (regional), and micro (local government, service users, care providers, and staff).[3] The Act was backed by an implementation support programme, a relatively new government initiative, which aimed to create a conducive environment for effective implementation.

1.4 Yet, despite this preparatory work on implementation readiness, a decade on from the Act it is clear that most of its goals have not been achieved:

- The Act's funding reforms were abandoned and its care cap proposals were never implemented;
- The number of carers' assessments has fallen below expectations;
- Investment in prevention has been deprioritised.

Our review of implementation of the Act found that short-term austerity and the real terms fall in social care spending from 2009 to 2016 severely limited the impact of the Act.[4]

[1] HM Government (2010) Building the National Care Service.
[2] Burn, E., Redgate, S., Needham, C., & Peckham, S. (2024). Implementing England's Care Act 2014: was the Act a success and when will we know? International Journal of Care and Caring, 8, (1): 47-63.
[3] Hunter, D.J., Redgate, S., Hudson, B. and Peckham, S. (2020) Do policy implementation support programmes work? The case of the Care Act 2014, Journal of Long-Term Care, 196–207.

ii). The Covid-19 pandemic

1.5 The Covid-19 pandemic highlighted weaknesses within local social care systems and central government's poor understanding of their complex organisation. Many excess deaths occurred in care homes and the dire state of the formal system of home care delivery was brought to the nation's attention. Staffing shortages, already intensified by Brexit, went from chronic to acute.

1.6 The weaknesses highlighted by the pandemic remain endemic:

- pressures of supply due to closures of care homes[5]
- poor data sharing between organisations
- lack of support and training for the care workforce
- the Care Quality Commission's (CQC's) operational performance has not recovered to pre-pandemic levels and is one of the factors noted in Dash's critical review of the CQC.[6]

iii). The Johnson government's plans for reform

1.8 As Prime Minister Boris Johnson promised that he had a social care plan ready that would fix social care 'once and for all'.[7] These proposals appeared to mark a strong commitment from government to ensure that the reforms could not be derailed due to lack of resources. However, the proposed Health and Care Levy was repealed before it could be enacted, and the care cap was postponed a few weeks later.

1.10 With the new Labour government announcing that the care cap will not go ahead, the long-term funding of social care continues to be unclear.

- Without a clear decision about the future of social care funding there is a great deal of uncertainty affecting how commissioners and care providers plan future service delivery.
- The threshold at which people become liable to pay for their care has not increased in line with inflation. As more people are drawn into paying for their care, potentially unmet and undermet needs will increase.
- People drawing on care, both now and in the future, as well as their families, are also greatly affected by continued funding uncertainty and are left unable to plan how they will meet future care costs.

2). What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?

2.1 The Workforce Strategy for Adult Social Care is not being implemented because of government indecision and lack of adequate investment in the sector.[8] This strategy was devised by key stakeholders in the sector, without direct government involvement. The lack of strategic workforce planning contributes to the workforce challenges that are reported annually by Skills for Care, in particular, high turnover, poor pay and working conditions.[9]

2.2 Professionalisation reforms are not being implemented; the planned 'Care workforce pathway' was first announced in 2021, then stalled, then was withdrawn after the change of government in July 2024. This

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[4] Burn, E., Redgate, S., Needham, C., & Peckham, S. (2024). Implementing England's Care Act 2014: was the Act a success and when will we know?. International Journal of Care and Caring, 8, (1): 47-63.
[5] Douglass, T., Zafar, S., and Glasby, J. (2024). What happens when care homes close? A review of the literature. International Journal of Care and Caring 8(3), pp. 471-488
[6] Dash, P. (2024) Review into the operational effectiveness of the Care Quality Commission: full report
[7] Campbell, D. (2019) 'Pledges to fix social care could cost Boris Johnson dearly', Guardian, 1 August, https://www.theguardian.com/uk-news/2019/aug/01/promising-to-fix-social-care-could-cost-boris-johnson-dearly
[8] Skills for Care (2024) A Workforce Strategy for Adult Social Care in England
[9] Skills for Care (2024) The state of the adult social care sector and workforce in England 2024.

stands in contrast to Scotland, Wales, and Northern Ireland, where the 'professionalisation' agenda continues to be pursued through a combination of pay rises, compulsory registration and training.[10]

2.3 Progress has been slow in pursuing integration of health and social care - due to a lack of sufficient funding, resources, staff and infrastructure required to pursue this agenda in a meaningful way.[11] [12]

2.4 There is a significant cost to local authority commissioners, employers and trade unions who have spent time and energy responding to government consultations and preparing for policy reforms that first stalled, then were withdrawn. Time and energy are both in short supply among both providers and commissioners. Our research with key stakeholders in the sector found that there was little capacity for any additional work under current conditions.[13]

3). What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

Unpaid carers - impact on income and finances

3.1 For unpaid carers, the costs of inaction on adult social care are severe. Our research has investigated the 'caring income penalty' by quantifying how unpaid care impacts people's income.[14] We use an innovative method (known as Individual Synthetic Control) to compare the income trajectories of unpaid carers with their synthetic counterparts - who shared similar characteristics but who did not provide care. We found that unpaid carers who provided 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.

3.2 The financial impact is also uneven:

- Younger unpaid carers (under 25 years old) faced the steepest penalty - losing up to £502 each month.
- Women providing 50+ hours of unpaid care per week experienced a 30% drop in their earnings compared to a 25% drop for men.
- Unpaid carers from ethnic minority groups experienced a lower absolute income penalty compared to white unpaid carers.

3.2 The intensity of care also affected people's finances differently:

- Unpaid carers who provide the lowest intensity of care (less than five hours per week) experienced an average monthly penalty of £44.
- unpaid carers who provided 5–19 hours of care per week saw reductions of up to £138.
- those providing 20–49 hours per week faced an income loss of up to £153 per month.
- households with a member providing 50+ hours of unpaid care per week experienced a significant 12% decrease in total household earnings - translating into hundreds of pounds per month.

3.4 These findings underscore the pressing need to develop more effective support systems for unpaid carers and the people they support. This includes access to adult social care for the people they support,

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[10] Hemmings, N., Oung, C., & Schlepper, L. (2022). New horizons: What can England learn from the professionalisation of care workers in other countries?

[11] Reed, S., Oung, C., Davies, J., Dayan, M., Scobie, S., Buckingham, H., Edwards, N., Curry, N., Dennison, R., & Kirkup, P. (2020). Integrating health and social care A comparison of policy and progress across the four countries of the UK.

[12] Hussein and Kispeter, forthcoming.

[13] Hussein and Kispeter, forthcoming.

[14] 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.

flexible working policies, and financial support. Our research has also indicated carers have a lower level of subjective well-being compared with non-carers, and the differences in wellbeing between carers and non-carers widens as local authority spending on adult social care decreases[15].

Unpaid carers - impact on those from migrant and racially minoritized communities

3.5 Our research has also highlighted the impact of unpaid care on economically marginalised households, especially on working-age members in full-time employment. There are particular pressures on those who migrated / whose family migrated – because wider family are not physically here to support with care:

> *"You have to understand that, as a family, this is it for us. We are the family in England. […] That's where it ends. That's where it starts and that's where it ends."* Person aged 50+ supporting ageing parents, Borders & Care study

3.6 Our research finds that migrant and racially minoritized communities do not necessarily prefer to have better access to existing state care. Rather, many would prefer to be properly economically supported to look after their family members - but this is challenging given the high cost of living. There are multiple, intersecting reasons why people report wanting to care for family themselves rather than access formal care services – these are to do with people's preferences but also to do with institutionalised racism in those services.

3.7 Unpaid carers with migrant backgrounds report that formal care services in England do not meet their family members' care needs. This is partly to do with the lack of person-centred care, which creates practical issues:

> *"My mum can't even express herself to those [domiciliary] carers; even though they can help, she won't be able to tell them exactly what she needs. But with me, she can communicate. […] There's no-one who can take better care of my mum than I can."* Unpaid carer for ageing mother

3.8 Carers describe how institutionalised racism means that their relatives experience a lack of care in both residential and homecare settings:

> *When we went to visit [an older family member in a care home], she says, "I don't like it here," and I was talking to one of the nurses and she says, "She's aggressive." And she says, "She won't eat, she won't do anything that we tell her." I says, "It's not aggressive. It's just [our people are] loud. They talk loud and a lot of people take that as aggression."* Older person caring for older sibling
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> *"One of the times, she [mother-in-law] was in the bedroom, I was caring for her, two nurses, senior nurses came in and said to my mother-in-law, "And where have you had this [illness] from?" Talking to her like she was […] a prostitute or a drug user. They didn't show any kind of respect towards her. When they came into the bedroom where I was caring for her, they'd always try and speak to me, and not my mother-in-law or my father-in-law. I had to actually pull them up – my father-in-law would be asking questions, and then they'd give me the answer, which was really embarrassing."* White British carer for Black mother-in-law

Care workers

3.9 Lack of reform also has an impact on the wellbeing of care workers. Pay is low, and breaches of the National Living Wage are common, due to unpaid travel time for example. The sector has been classed as low-paid by the Low Pay Commission since 1988.

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[15] Zhang, Y., Bennett, M. R., & Yeandle, S. (2021). Longitudinal analysis of local government spending on adult social care and carers' subjective well-being in England. BMJ open, 11(12), e049652. https://bmjopen.bmj.com/content/11/12/e049652

3.10 Failure to address the underlying issues causing the recruitment and retention crisis means that the sector is reliant on recruiting overseas workers. This increasingly leads to a two-tier workforce, with migrant workers on the Health and Care Worker Visa tied to employers and not having full employment (and human) rights while in the UK. There are widespread reports about exploitation of migrant care workers by some employers.

4). Where in the system is the cost of inaction on adult social care reform being borne the most?

4.1 Our research finds that in order to have a flourishing social care ecosystem,[16] it's essential not just to nurture the visible parts of the system, such as the mammals and birds - we liken these to the formal parts of the social care system, e.g. care homes. A flourishing ecosystem also needs lots of invisible activity - the micro-organisms that make the soil rich and fertile. These parts are all the community activities which aren't necessarily thought of as part of the formal social care system, but which enable people to have purpose, meaning and provide a lot of day-to-day support. These could include faith groups, community centres, sports clubs, and neighbourhood networks.

4.2 Our research finds that local community groups have stepped in to 'fill the gaps' in reduced care provision for older people, due to austerity-driven funding cuts to local services and support. In the case of migrant and racially minoritized populations, support by community groups is especially needed and requested by older populations themselves, because the groups provide person-centred care support, which larger organisations or state services do not:

> *"People have got different needs, and they need to be met in different ways. […] For example, when we're doing the care plan for our clients, they don't eat microwaved food, ready meals. They eat freshly cooked food, and that needs to be part of the care plan. […] They've been eating that way for their whole life, so we need to respect that that's the way they're living. They can't just change because they need care now."* Community group manager and domiciliary care provider.

4.3 Community groups highlight a range of unmet care requirements: food needs (which directly impact nutritional requirements), personal care (bathing routines, hair care), religious customs, and language needs.

4.4 Providing such person-centred support is crucial to ensuring that people feel cared for and connected. Community groups stepping in to provide this support note that they have to do so because existing (state and market services) are typically unwilling to adapt their 'standard' provision and also do not have the capacities to provide such care, because of severe under-staffing and under-resourcing.

4.5 Community groups step in to help older people who are digitally excluded and who don't speak English to complete the detailed and complex online forms to access what state support is available. Migrant support groups report that Black migrant populations are particularly under-served by state services; other local organisations report higher need among Black African and Caribbean populations who are still struggling with the disproportionately racialised impacts of the COVID-19 pandemic.

4.6 The impact on these typically small, under-resourced community organisations is unsustainable. Community group leaders report being 'encouraged' by local authorities (as well as populations themselves) to provide this care. Typically, community groups provide such care via staff from within the populations themselves, so they are contributing to building and upskilling local communities. However, groups are expected to provide this care without any additional funding which is simply unsustainable:

[16] Burn, E., Needham, C. (2023) What does the concept of an ecosystem offer to social care? A narrative review of the ecosystem literature. Centre for Care Working Paper 2, CIRCLE, Sheffield: University of Sheffield.

"no-one can work for nothing", Leader of local community group

Group leaders discuss regularly working 10-16 hours a day, unpaid:

> *"It's very hard, it's very hard. Myself, I'm on Universal Credit, I rely on benefits even though I'm helping other people. […] Because if I go on a full-time paid job, I will [have to] leave this, and no one will be here to help these people."* Local community group leader supporting migrants

4.7 Local groups are unable to compete with large, national organisations for grant funding; they cannot afford to pay grant writers; they do not have the resources to adapt applications to meet multiple eligibility frameworks. They struggle with a lack of local funds – where before, it was possible to obtain support from and secure contracts with local councils, they report being unable to do so now because of not meeting high minimum income thresholds.

4.8 Local community groups urgently need funding to provide care but group leaders also called for better care resourcing across the board to ensure those in need within their communities will receive properly resourced and tailored care from existing state services.

4.9 Our research participants also reflected upon institutionalised discrimination and racism within the health and care system and how it intersects with the ongoing impacts of austerity:

> *"If you're inclined to feel like people are not deserving of services, so if you have got your own prejudice against people who have sought asylum in this country, or who are from an ethnic minority, then you're much, much less likely to give a good level of care to somebody. […] And it does involve people going beyond the routine. It is harder to do a GP appointment with somebody if you need to get an interpreter on the phone, and it's hard to get one. It takes longer. […] So it does involve a level of commitment from people, to spend the time, and potentially resources to support people well."* Local provider for refugee support services

4.10 Although this inquiry is focused on the social care system, it is important to note that the health and care needs of people with migrant backgrounds (especially recently arrived migrants) are very much affected by the hostile immigration system.

- One older participant described arriving in the UK as a refugee fleeing war, but in relatively good physical health; however, since being here, her health has deteriorated because of the stresses of navigating the hostile immigration environment, resulting in significant economic and housing precarity.
- Another older research participant who came to the UK, also fleeing war, violence and precarity, is now the primary carer for her school-age granddaughter. She juggles her caring responsibilities, multiple health needs, and is expected to attend ESOL classes, in order to eventually find paid work. These classes do not meet her needs as she was unable to complete her childhood education; it is also physically challenging for her to attend in poor health. The system is experienced as punitive, and exacerbates people's health and care needs:

> *"I have been experiencing a lot of problems. I wake up in the morning and go [to ESOL classes]. Sometimes, I would be coughing a lot until I vomited on the road. I would be stuck on the way and feel like my legs are refusing to go. [But] when they enrol you for education, […] the first thing they tell us is, if you are late for more than 15 hours in a month, you should just know that [you] will not get allowances from the Job Centre."* Older person

4.11 Under 3, we have outlined the cost of inaction borne by unpaid carers. Unpaid carers are also providing vast amounts of care and support to 'fill gaps' in an under-resourced care system. Our research with Carers UK has highlighted that unpaid carers in the UK are now providing care worth £184.3 billion a year- a huge increase of £64.9 billion since 2011 because families are providing more care than ever

before. The combined NHS budget across the four nations of the UK in 2021/2022 was £189 billion. Carers in the UK are providing the value of care equivalent to a second NHS.[17]

About the Centre for Care

This response is provided by members of the ESRC-funded Centre for Care. The Centre for Care is a research-focused collaboration between the Universities of Sheffield, Birmingham, Kent and Oxford, the London School of Hygiene & Tropical Medicine, the Office for National Statistics, Carers UK, the National Children's Bureau, and the Social Care Institute for Excellence. Funded by the Economic and Social Research Council, with contribution from the National Institute for Health Research (NIHR) and Department of Health and Social Care, as one of its flagship research centres, it works with care sector partners and leading international teams to provide accessible and up-to-date evidence on care – the support needed by people of all ages who need assistance to manage everyday life.

Led at the University of Sheffield by Centre Director Professor Kate Hamblin and Deputy Director Professor Nathan Hughes, our work aims to make a positive difference in how care is experienced and provided in the UK and internationally by producing new evidence and thinking for policymakers, care sector organisations and people who need or provide care. In studying care, we focus on ways of improving wellbeing outcomes and on the networks, communities and systems that support and affect people's daily lives, working closely with external partners.

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December 2024

[17] Petrillo, M Bennett, M. and Zhang, J. (2024). Valuing Carers 2021/22: the value of unpaid care in the UK.