Written evidence submitted by the Understanding Society, the UK Household Longitudinal Survey (ASC0029)

Health and Social Care Committee inquiry 2024: Adult Social Care Reform: The Cost of Inaction

1. Introduction

1.1. Understanding Society, the UK Household Longitudinal Study, is a world-leading longitudinal survey of continuity and change in UK life. From an initial sample of around 40,000 households, the same people are invited to participate in annual surveys. Together with its predecessor, the British Household Panel Survey, the data now span more than 30 years. Understanding Society is based at the Institute for Social and Economic Research at the University of Essex. It is an important part of CLOSER, a partnership of leading social and biomedical longitudinal population studies in the UK (www.closer.ac.uk).

1.2. Understanding Society is primarily funded by the Economic and Social Research Council, part of UK Research and Innovation, and receives funding or support from a number of government departments, devolved administrations and agencies. Anonymised data from the survey are made available to registered researchers from across academic, government, charities, think tanks and business to use in their own research.

1.3 We have identified research which uses Understanding Society data which is relevant to the Committee's questions on:

- the impact of inaction on patients and the public / how people's lives might change with social care reform
- where is the cost of inaction felt the most
- the contribution of adult social care to the economy.

2. Summary

- Unpaid carers are at greater risk of being in poverty
- Almost all caregivers report worse mental health than non-caregivers
- Carers have a lower level of subjective wellbeing compared with non-carers
- Local authority spending on care reduces the wellbeing difference
- The physical health of unpaid carers deteriorates over time
- Carers are ageing, and care remains classed and gendered
- Inaction is felt most by older people, women, and/or those with lower socioeconomic status
- The number of carers in the UK may have been significantly underestimated
- Unpaid care saves government an estimated £23 billion a year

3. Impact of inaction on patients/public

3.1 In this section, we set out evidence of the impact on carers' mental health, physical health, and economic circumstances. Inaction would see these effects persist and potentially worsen. Reform of social care has the potential to lessen these effects.

3.2 Unpaid carers face an elevated risk of being in poverty: in 2019 and 2020, around one-quarter of unpaid child-carers (those caring for children, 24%) and unpaid social-carers (those caring for other

family or friends, 28%) were living in relative poverty after housing costs, compared to 17% of the overall adult population.

3.3 One in four adults living in poverty were unpaid carers – 1.9 million child-carers and 0.9 million social-carers.

3.4 Much of the hardship faced by unpaid carers reflects a tension between paid work and unpaid care, along with inadequacies in the benefits system and statutory leave policies. Many unpaid carers are forced to leave paid work or reduce their working hours, often with little in the way of income replacement. Some unpaid carers may fall into poverty for other reasons even if they stay in paid work.

3.5 Almost all caregivers report lower mental health than non-caregivers. Only those who do not live with the person they care for, and provide lower intensity care – fewer than 20 hours a week – report better mental health. However, most unpaid carers are providing care for people they don't live with such as parents, other relatives, or friends.

3.6 Caregiving strains are more intense for those providing care for longer hours. Once caregiving becomes intense, caregivers report similar levels of distress regardless of the location of care.

3.7 Carers have a lower level of subjective wellbeing compared with non-carers, but differences in subjective wellbeing decrease with local government spending on adult social care. Carers' subjective wellbeing was similar to that of non-carers in high-spending (on adult social care) local authorities, and lower in other areas. The moderating effect of adult social care spending is found among people who care for 35+ hours per week.

3.8 The physical health of unpaid carers deteriorates over time, more than it does for non-carers, and this negative effect increases over time – but some types of health fluctuate.

3.9 Self-reported health and loss of sleep are worse one year after starting to have caring responsibilities, but the negative effect gets smaller two years later, increasing again after three years. This suggests that there may be a period of time when carers are adapting to their new role.

3.10 Physical health and lack of concentration continuously deteriorate over time for carers compared to non-carers, suggesting a cumulative effect.

3.11 Physical health is worst for co-carers (i.e. the carer and care recipient simultaneously care for each other) where carer and care recipient have unmet needs for care. It is better for those providing low-intensity care, and who are in better socio-economic circumstances.

3.12 Seven in ten older carers (80+) have long standing health problems of their own with nearly half having difficulty with moving about at home, walking or lifting carrying or moving objects.

3.13 Around a quarter of older carers are caring for more than 35 hours a week while a further 13% are caring for more than 20 hours a week.

3.14 These differences across carers may suggest that policies designed to support them need to better acknowledge that a 'one size fits all' solution may not be adequate. For this, targeting as well as tailoring care service may be necessary as some carers are a greater risk than others.

4. Where inaction is felt the most

4.1 Evidence shows that carers are ageing, and care remains classed and gendered. Inaction is therefore felt most by older people, women, and/or those with lower socioeconomic status.

4.2 There are over two million carers aged 65 and over, and almost a third of over-80s are carers. Figures which are already five years old suggest there were 970,000 carers aged 80 and over.

4.3 Older carers are among those most likely to care at high levels of intensity, especially those aged 80 and over caring for a co-resident partner. Over 37% of carers aged 80+ are providing 20 hours or more care a week, while 34% are providing 35 hours or more.

4.4 Nearly two thirds of older carers themselves have a health condition or disability, with 72% of older carers report feeling pain or discomfort, rising to 76% for those who provide 20 or more hours of care a week.

4.5 Female caregivers are more susceptible to role overload and 'captivity' – the feeling of not having a choice in engaging in caregiving.

4.6 Female caregivers who provide care for more than 20 hours a week for parents or other loved ones report worse mental health than their male counterparts.

4.7 Increasing longevity has led to a rising number of adult children who are at higher ages when they provide care for their parents. Even past retirement age, parent care remains classed and gendered, with women from lower social classes having the highest likelihood of providing intensive parent care in old age.

4.8 People with lower levels of education are more likely to provide intensive care and those from higher educational groups having a lower likelihood of doing so. This is consistent with parent-child relationships being closer in lower-class families and with the idea that people in higher classes can buy care services.

4.9 People with a middle level of education are more involved in caring for their parents than those from the other two educational groups. It may be that adult children who have had or expect to inherit significant sums from their parents are more likely to provide care (making the middle group more involved than the lower educational group), and that more highly educated adult children tend to live further away from their parents (explaining their lower level of involvement in parent care).

4.10 In addition to all of the above, discrepancies between those receiving care and those who report that they are caring for someone they live with suggest that many carers may be 'hidden'. Where someone reported receiving informal care, this was only confirmed by the person providing that care in 37.5% of cases. In other words, carers may not think of what they are doing as 'care'. (By contrast, where a carer reports giving care, this is confirmed by the recipient in 78.7% of cases.) The number of co-resident carers in the UK may therefore be 3.24 million higher than previously thought.

5. Contribution of caring to the economy

5.1 Understanding Society does not have figures relating to the contribution adult social care makes to the economy, but carers aged 80 and over provide 23 million hours of unpaid care a week – 1.2 billion hours of care a year – saving government an estimated £23 billion a year through unpaid care.

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