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### Valuing Carers 2021

Zhang, Jingwen; Petrillo, Maria; Bennett, Matt

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O Centre for Care

# Valuing Carers 2021

## Northern Ireland

Dr Jingwen Zhang Dr Maria Petrillo Professor Matt Bennett













UNIVERSITY<sup>OF</sup> BIRMINGHAM

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# Foreword

### Craig Harrison, Carers NI

Across Northern Ireland, more than 220,000 people are providing unpaid care for a sick or disabled family member, friend or neighbour – representing roughly one in eight people.<sup>1</sup> The number of people performing the most intense unpaid caring roles has increased significantly during the last decade, putting more and more pressure on them to cover gaps in a rapidly deteriorating Health and Social Care system.

We have always known that unpaid carers make an immense contribution, but this research report underlines the sheer scale of it – showing that unpaid carers in Northern Ireland are now providing care worth an astonishing **£5.8 billion per year**.

To put it in perspective, that is the equivalent of around 85% of the Department of Health's entire budget for 2021/22. Put another way, it is nearly five times more than the amount spent providing social care services across the whole of Northern Ireland that year. And our calculation is likely an underestimate.

It is not an exaggeration, then, to say that our Health and Social Care system would collapse without the care being provided for free by family members, friends and neighbours every day. If our GP surgeries are already too full, social care caseloads too long and A&E departments too crowded, how much worse would it be if our unpaid carers disappeared even for a few days? The system would fall apart. In return for propping up public services, our carers should, as a minimum, be getting the basic support they need to take breaks from caring, look after themselves and lead a life of their own, but far too many are denied that.

They're going months, often years, without a meaningful break to recharge their batteries. They're being driven to exhaustion and burnout, their mental and physical health devastated by a lack of replacement care and other support services. And they're being abandoned to lives of poverty and hardship by insurmountable barriers to employment and an inadequate social security system.

We must do better, and the onus is particularly on political and health service leaders to deliver the practical and policy changes required to improve carers' lives. Northern Ireland would be in deep trouble without our unpaid carers, and it is time we gave them the recognition, help and support they deserve.



# Introduction

**Professor Matt Bennett** Centre for Care, University of Birmingham



To mark Carers Rights Day 2023, we have collaborated with Carers Northern Ireland on this report, which puts a financial value to the contributions of unpaid carers in Northern Ireland<sup>2</sup>. Care is often provided as an expression of love. Therefore, it is difficult to measure it, or put a monetary value on it. It is, however, one way to acknowledge and raise awareness of the vital contributions unpaid carers make to the Health and Social Care system.

Across the UK, millions of unpaid carers support a family member, friend or neighbour to manage daily activities, usually due to long-term illness, disability, or older age. Thousands of people become unpaid carers every day, many of whom balance paid work and other responsibilities alongside the care they provide<sup>3</sup>. Everyone, regardless of background and personal circumstances, will experience unpaid care at some point in their lives<sup>4</sup>. However, exactly when this will happen is often difficult to know – it can happen overnight, as the result of an accident or sudden illness, or more gradually through a deteriorating condition. Yet the invaluable support unpaid carers provide often has significant impacts on their financial wellbeing, health and social lives<sup>5</sup>.

This new research highlights the incredible increasing financial value of unpaid care in Northern Ireland. Unpaid carers in Northern Ireland are providing care worth an unbelievable £5.8 billion a year – to put this into perspective, the Department of Health's budget in Northern Ireland in 2021/2022 was around £6.8 billion. The monetary contributions made by carers has increased by 42% in the last decade. People are also providing more hours of unpaid care than ever before – an increase across all Health and Care Trusts in the region. The findings in this report highlight the important role of unpaid carers in society and the savings they make to health care budgets.

This research uses data from Census 2011 and Census 2021 from the Northern Ireland Statistics and Research Agency (NISRA) and the UK Household Longitudinal Study (Understanding Society) to inform our estimates. We are incredibly grateful to NISRA and the ESRC, respectively, for funding, collecting and making these data assets available to the public.

I'm incredibly grateful to my fantastic colleagues for the enthusiasm, generosity and hard work they put into this research – it has been a collaboration between Dr Jingwen Zhang, Dr Maria Petrillo and myself in the Centre for Care; and Craig Harrison (Carers Northern Ireland), Fiona Collie and Richard Meade (both at Carers Scotland).

We're all also especially grateful to Professor Catherine Needham for invaluable insights and comments on an earlier version of this report.

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Professor Matt Bennett, Centre for Care, University of Birmingham

<sup>2</sup> The authors gratefully acknowledge the support of the Economic and Social Research Council (award reference ES/W002302/1).

<sup>3</sup> Petrillo, Bennett and Pryce (2023). Cycles of caring: transitions in and out of unpaid care. London: Carers UK.

<sup>4</sup> Zhang, Y., Bennett, M. R., and Yeandle, S. (2019) 'Will I Care: The likelihood of being a carer in adult life'. London: Carers UK.

<sup>5</sup> 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), 611-630.

# Key findings

Valuing Carers 2021: Northern Ireland Dr Jingwen Zhang, Dr Maria Petrillo and Professor Matt Bennett

The economic value of the contributions made by unpaid carers in Northern Ireland is unprecedented.

- The economic value of the contributions made by unpaid carers in Northern Ireland is estimated to be a staggering £5.8 billion<sup>6</sup>. This represents a 42% increase in real terms since 2011, highlighting the essential and growing role of unpaid carers in the region's economic landscape.
- The economic value of the contributions made by unpaid carers in Northern Ireland is the equivalent of around 85% of the Department of Health's budget for 2021/2022, which was £6.8 billion. Remarkably, this figure is nearly five times the expenditure allocated to social care during that fiscal year<sup>7</sup>.



6 This is likely to be an underestimation. Please see methodological detail in the 'Finding and Methodology' section, and robustness checks in the appendix.

7 Department of Finance (2021). Northern Ireland Budget 2021-2022.

- The figures underscore the significance of the contributions made by unpaid carers, illustrating how they save the public purse enormous sums every week, day and hour of the year:
  - » £5.8 billion per year
  - » £112.0 million per week
  - » £16.0 million per day
  - » £0.7 million per hour.
- The increase in the economic value of unpaid care mainly results from the rise in the number of hours of care provided by unpaid carers.
- The intensity of unpaid care has increased sharply over the last decade in Northern Ireland.
  - » The proportion of people providing 20-49 hours of care per week was 3.0% in 2021, up from 2.2% in 2011, increasing the value of the care they provided by £940 million
  - » The proportion of people providing 50 or more hours of care per week was 4.0% in 2021, up from 3.6% in 2011, increasing the value of the care they provided by £1.4 billion.
- The demand for unpaid care has intensified due to several key factors:
  - » Demographic shift: The proportion of people aged 65 and older increased from 14.6% in 2011 to 17.2% in 2021
  - » Health challenges: The percentage of people grappling with long-term health problems or disabilities has risen, affecting one in four people in 2021
  - » Domiciliary care decline: The decline in support from domiciliary care services further accentuates the need for unpaid care, emphasising the necessity to address this growing demand.



# Findings and methodology

The 2021 Census included the following question on the provision of unpaid care:

Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age? Exclude anything you do as part of your paid employment.

The data is drawn from Census 2011 and Census 2021 in Northern Ireland to provide comprehensive information on the monetary value of the time that unpaid carers dedicated to looking after or providing help to family members, friends, neighbours or others in need.

Quantifying the precise value of unpaid care is challenging, as unpaid care holds an intrinsic value that transcends the monetary value. It often serves as an expression of unconditional love and deep respect



for those receiving care. Nonetheless, it remains imperative to acknowledge the significant contributions of unpaid carers to our society. This report estimates the monetary value of unpaid care to powerfully demonstrate that unpaid carers are a vital part of Northern Ireland's Health and Social Care (HSC) system.

Table 1 shows the number and age-standardised proportions<sup>8</sup> of people providing unpaid care by hours of care in Northern Ireland. After accounting for the effects of a growing population and changes in age structure, the data suggest that the proportion of the population aged five and over providing unpaid care remained largely stable over the past 20 years and decreased slightly from 13.2% in 2011 to 12.8% in 2021.

However, there has been a change in the intensity of care over time. Table 1 shows that while there was a reduction in the proportion of people providing care for 19 hours or less, the percentage of people who provided 20-49 hours per week increased noticeably from 2.2% in 2011 to 3.0% in 2021. The proportion of people who provided the most intensive care (50 or more hours per week) also increased from 3.6% in 2011 to 4.0% in 2021.

8 Age-standardised proportions are used throughout the report wherever proportions of unpaid carers are mentioned. The age composition affects the proportion of unpaid carers within a population, making age-standardised proportions more appropriate and valid than crude percentages when making comparisons between populations over time, as it can remove the effect of population ageing.

	2021 No. of unpaid carers	2021 (%)*	2011 No. of unpaid carers	2011 (%)*	2001 No. of unpaid carers	2001 (%)*
19 hrs or less	100,783	5.7%	122,301	7.4%	109,958	7.4%
20-49 hrs	52,743	3.0%	35,369	2.2%	27,933	1.9%
50 hrs or more	68,690	4.0%	56,310	3.6%	46,543	3.4%
Total	222,216	12.8%	213,980	13.2%	184,434	12.8%

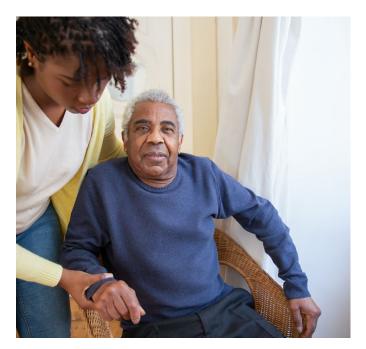
### Table 1: Total number and age-standardised proportions of unpaid carers by hours of care inNorthern Ireland, 2001-2021

Source: Northern Ireland Statistics and Research Agency (NISRA) Census 2021, 2011 and 2001. Note: \* indicates age-standardised proportion (authors' calculation).

To calculate the economic value of unpaid care in Northern Ireland, we first used the total number of unpaid care hours contributed by all unpaid carers in each Health and Social Care Trust (HSCT) per year multiplied by the HSCT-specific unit cost for replacement care<sup>9</sup>. Summing up the values from all five HSCTs provided the overall economic value of unpaid care in Northern Ireland. The unit costs for Belfast, Northern, South Eastern, Southern and Western HSCT were £21.2, £19.9, £17.8, £20.0, and £18.0 per hour respectively in 2021<sup>10,11</sup>. In contrast, for 2011, the corresponding unit costs were £13.4, £14.8, £13.4, £14.7, and £14.6 per hour, respectively<sup>12</sup>, consistent with the official estimates of the actual cost per hour of providing domiciliary care (for a full explanation of the method used to calculate the final value of caring activities, see Appendix B).

As Table 2 shows, the economic value of unpaid care in Northern Ireland rose remarkably by 42.3% from 2011 to 2021. The contribution of unpaid carers' in Northern Ireland in 2021 translated into substantial savings for the public purse every week, day and hour of the year:

- £5.8 billion per year
- £112.0 million per week
- £16.0 million per day
- £0.7 million per hour.



9 Our estimates for the value of care are based on the overall population of people aged five years and above. While young carers are not able to work for a wage, we calculated their costs because the important support they provide is still money saved on health care. See Appendix B, Tables B.3 and B.4 for the value of unpaid care computed on the adult population.

10 Department of Health, Northern Ireland (2020). Community Services Indicators - Trust Unit Cost 19-20.

- 11 The unit costs in 2021 and 2011 are expressed in nominal terms, and not adjusted for inflation. It should be noted that there were no data collections by the Department of Health (Northern Ireland) on the unit cost of domiciliary care in 2020/21 or 2021/22. Therefore, we used the unit cost in 2019/20 as a conservative estimate for the unit cost in 2020/2021. We also created our own estimate of the unit cost in 2020/21 based on historical data prior to 2020 as a robustness check, which is reported in Appendix B, Table B.5.
- 12 Department of Health, Northern Ireland (2011). Community Services Indicators Trust Unit Cost 10-11.

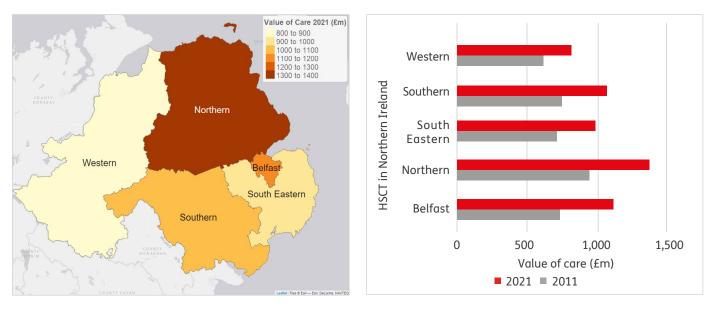
 Table 2: Nominal value of unpaid carers' contributions and real change in carers' contributions (%)

 in Northern Ireland, 2011 and 2021

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	Change 2021-2011 (%)
19 hrs or less	100,783	122,301	580	610	-18.2%
20-49 hrs	52,743	35,369	1,776	836	82.6%
50 hrs or more	68,690	56,310	3,470	2,073	43.8%
Total	222,216	213,980	5,826	3,519	42.3%

Source: Authors' calculations based on Census 2011, and 2021 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). Columns 'Value 2021' and 'Value 2011' represent the nominal value of unpaid carers' contributions (not adjusted for inflation) to provide discrete estimates for the value of unpaid care in 2021 and 2011. However, to enable comparisons in the value of unpaid care between 2011 and 2021, the percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH). More details on the methodology are provided in Appendix B (Table B.1).

Figure 1 shows that the increase in the value of unpaid care is consistent across all Health and Social Care Trusts (HSCT) in Northern Ireland, with Belfast HSCT experiencing the sharpest increase (by 52%<sup>13</sup>). Southern HSCT and Northern HSCT also observed a considerable 44% increase in the value of unpaid care.



#### Figure 1: Value of unpaid carers' contributions by Health and Social Care Trust in Northern Ireland

Source: Authors' calculations based on the Census 2011 and 2021 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). The unit cost is the real value of unpaid carers' contributions (adjusted for inflation). The figure on the left illustrates the geographical variation in the value of unpaid carers' contributions in 2021, while the figure on the right illustrates the changes in value from 2011 to 2021.

13 The percentage changes in value of care by HSCT were estimated in real terms (adjusted for inflation).

# Comparison with England and Wales



Table 3 presents the comparisons in the proportion of unpaid carers and the value of care between Northern Ireland, England, and Wales<sup>14,15,16</sup>. At the time of writing, the data from the Scottish Census 2021 has not been released, so the comparison between Northern Ireland and Scotland is not presented in this report.

- Northern Ireland had a higher percentage of people providing unpaid care compared to England and Wales in both 2021 and 2011.
- Northern Ireland saw an increase in the absolute number of unpaid carers and did not experience a substantial decrease in the percentage of unpaid carers (-0.4%) over the last decade, unlike England (-2.5%) and Wales (-2.5%)
- Unpaid carers provided more hours of care in Northern Ireland than in England and Wales. In Northern Ireland, 7% of people provided 20 or more hours of care per week in 2021, compared with 4.5% in England and 5.8% in Wales. Northern Ireland also had a sharper increase in the number of people providing 50 or more hours of care per week (from 3.6% in 2011 to 4% in 2021) compared with the figures in England and Wales
- The increase of 42.3% in the monetary value of care in Northern Ireland from 2011 to 2021 was also the biggest among the three jurisdictions.

<sup>14</sup> For detailed information on the value of unpaid care in England and Wales, please refer to: Petrillo and Bennett (2023), Valuing Carers 2021: England and Wales.

<sup>15</sup> Note that the Census 2021 in Northern Ireland (NISRA) and the Census 2021 in England and Wales (ONS) have narrower answer categories for more intensive care (20-34 hours a week; 35-49 hours a week) compared with the Census 2011 (20-49 hours). Whilst Census 2021 in Northern Ireland only has one option, 1-19 hours a week, Census 2021 in England and Wales divides this range into two options, 9 hours or less and 10-19 hours a week.

<sup>16</sup> The unit costs used for calculating the value of care in England and Wales are produced by the Personal Social Services Research Unit (PSSRU). The methodology of calculating the unit costs adopted by the PSSRU and the Department of Health (Northern Ireland) are largely comparable; however, the former provides estimates at the national level, while the latter provides specific costs for each HSCT in Northern Ireland. The PSSRU unit costs also represent the cost per hour on weekdays, whilst the DoH (NI) unit costs represent average costs regardless of the time of the service. These differences should be considered when comparing the value of care in England and Wales with Northern Ireland. We also calculated the value of care in Northern Ireland using the PSSRU unit cost as a comparison (see Appendix B, Table B.6).

	2021 % of unpaid carers	2011 % of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	Change in value 2021- 2011 (%)
Northern Ireland					
19 hrs or less	5.7	7.4	580	610	-18.2%
20-49 hrs	3.0	2.2	1,776	836	82.6%
50 hrs or more	4.0	3.6	3,470	2,073	43.8%
Total	12.8	13.2	5,826	3,519	42.3%
England					
19 hrs or less	4.4	7.2	16,262	17,386	-21.4%
20-49 hrs	1.8	1.5	44,250	21,667	71.6%
50 hrs or more	2.7	2.7	91,310	58,791	30.5%
Total	8.9	11.4	151,822	97,845	30.3%
Wales					
19 hrs or less	4.7	7.4	969	1,316	-38.1%
20-49 hrs	2.2	1.9	2,852	1,578	51.8%
50 hrs or more	3.6	3.7	6,944	4,855	20.1%
Total	10.5	13.0	10,766	7,749	16.7%

 Table 3: Proportion of unpaid carers and value of care by hours of care and jurisdiction, 2021 and 2011

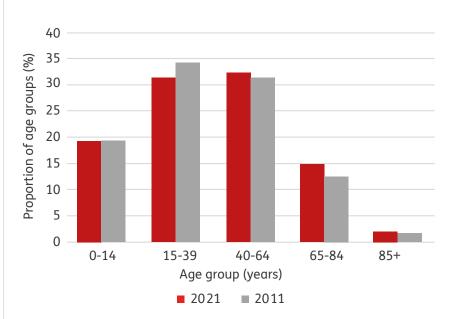
Source: The proportion of unpaid carers and value of care by hours of care in England and Wales was taken from the report, Valuing Carers 2021: England and Wales (Petrillo and Bennett, 2023). Columns 'Value 2021' and 'Value 2011' are the nominal values of unpaid carers' contributions (which is not adjusted for inflation). The percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH).

# Why has the intensity of unpaid caring increased in Northern Ireland?

### Change in age structure in Northern Ireland

The increase in the percentage of people who provided 20 or more hours of unpaid care aligns with the process of population ageing. The number of older people aged 65 years and above in Northern Ireland increased from 263,720 in 2011 to 326,477 in 2021 – an increase from 14.6% of the population in 2011 to 17.2% in 2021 (see Figure 2). The percentage of people aged 85 and above also increased substantially from 1.7% to 2.1% between 2011 and 2021.

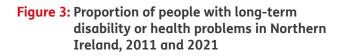


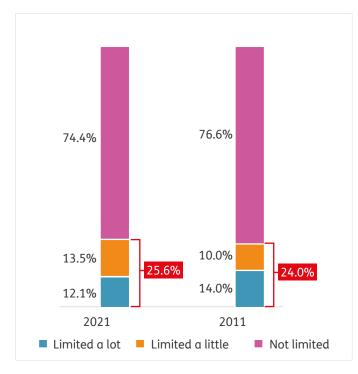


Source: Authors' calculations based on the Census 2021 and Census 2011 in Northern Ireland (NISRA).

### Worsening of physical functioning and health status

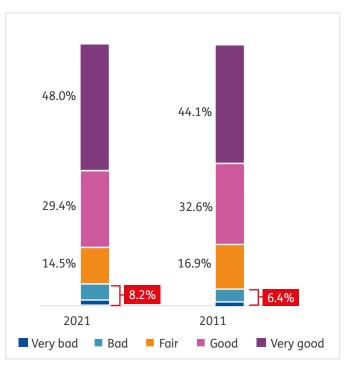
Census 2021 data further shows that the number of people with a limiting long-term health problem or disability in Northern Ireland had risen by 88,373 from 2011 to 2021, reaching nearly one in four people of the population (25.6%) (see Figure 3). Moreover, the proportion of people with 'bad' and 'very bad' general health increased from 6.4% in 2011 to 8.2% in 2021 (see Figure 4). The growth in long-term illness and disability, as well as the worsening of general health, increase the demand for care – both in the form of formal services and unpaid support from carers.





Source: Authors' calculations based on the Census 2021 and 2011 in Northern Ireland (NISRA). All the proportion are age standardised.

Figure 4: The distribution of general health status in Northern Ireland, 2011 and 2021



Source: Authors' calculations based on the Census 2021 and 2011 in Northern Ireland (NISRA). All the proportion are age standardised.

### The decline in the support from domiciliary care services

Domiciliary care services play a crucial role in supporting people with long-term health issues and disabilities to live well at home. They are also the major substitute, and support, for unpaid care, but despite the increase in care demand in Northern Ireland outlined above, support from domiciliary care services has been declining and increasingly difficult to access. This is illustrated through a number of data points:

- The number of people receiving domiciliary services<sup>17</sup> reduced from 23,522 in 2011 to 22,693 in 2021. In particular, the number of people receiving domiciliary care from the statutory sector nearly halved (-47.1%) between 2011 and 2021
- The number of people in Northern Ireland waiting for a domiciliary care package grew from nearly 700 in 2016, to more than 1,200 in 2017-18<sup>18</sup> and to over 3,000 by February 2022<sup>19</sup>
- The social care staff vacancy rate among Health Trusts grew from 1.7% in 2011 to 10.4% in 2021<sup>20</sup>, and independent providers have faced similar recruitment and retention issues.

COVID-19 exacerbated all these trends, with the suspension of some domiciliary care packages at various stages during the pandemic and additional pandemic-related staff shortages<sup>21</sup>.

These challenges have meant that demand for domiciliary care services has significantly outstripped supply, putting more pressure on unpaid carers to fill the care gap.



<sup>17</sup> The number of clients receiving domiciliary services encompasses clients of both independent and statutory service providers.

<sup>18</sup> Marie Curie (2019). Every minute matters: The impact of delayed discharges from hospital on terminally ill people in Northern Ireland.

<sup>19</sup> Assembly Written Question 29580/17-22. See: https://aims.niassembly.gov.uk/questions/printquestionsummary.aspx?docid=367566.

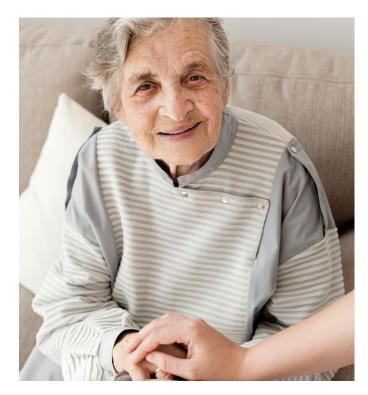
<sup>20</sup> Department of Health. Northern Ireland health and social care (HSC) workforce vacancies.

<sup>21</sup> Department of Health (2022). Statistics on community care for Adults in Northern Ireland (2021 - 2022)

## Changes in the Census unpaid care-related question

Differences between the unpaid care question wording and answer categories between Census 2011 and Census 2021 in Northern Ireland may also affect people's perception of their unpaid care role and intensity ('intensity' measured in *hours* of unpaid care). Table 4 presents the question wording and answer categories in the Census 2021 and 2011 questionnaires.

Census 2021 provides respondents with a narrower range of answer categories for unpaid care hours per week by splitting the 20-49 hours of care into two new categories (20-34 hours a week; 35-49 hours a week). This change could potentially affect how carers perceive the number of hours of care they provide. In addition, Census 2021 uses the wording "mental health conditions or illness" rather than "mental illhealth/disability" in Census 2011. As "mental health conditions" is a broader term than mental ill-health/ disability, this inconsistency may lead to more hours of unpaid care being reported in 2021 compared to 2011.



#### Table 4: Change in the question wording and answer categories (Census 2011 and Census 2021)

Census 2011	Census 2021
Do you look after, or give any help or support to family members, friends, neighbours or others because of either: - long-term physical or mental ill-health / disability? - problems related to old age? Do not count anything you do as part of your paid employment.	Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age? Exclude anything you do as part of your paid employment.
<ul> <li>No</li> <li>Yes, 1-19 hours a week</li> <li>Yes, 20-49 hours a week</li> <li>Yes, 50 hours or more a week</li> </ul>	<ul> <li>No</li> <li>Yes, 1 to 19 hours a week</li> <li>Yes, 20 to 34 hours a week</li> <li>Yes, 35 to 49 hours a week</li> <li>Yes, 50 hours or more a week</li> </ul>

# Recommendations

This report underlines the enormous contribution of unpaid carers in Northern Ireland, who are propping up the Health and Social Care (HSC) system and saving the Stormont budget from total collapse – at a significant cost to their own health, wellbeing, opportunities and quality of life.

As wider research shows:

- 25% of carers describe their mental health as 'bad' or 'very bad' and 50% say their physical health has suffered due to unpaid caring<sup>22</sup>
- One in three unpaid carers haven't had a break from caring during the last 12 months<sup>22</sup>
- One in four unpaid carers are living in poverty significantly more than Northern Ireland's non-carer population (16%) and higher than the carer poverty rate in the rest of the UK (23%)<sup>23</sup>
- Just 34% of unpaid carers are in some form of employment, significantly less than the general adult population<sup>24</sup>, and a key driver of financial hardship among carers.

Government, health and social care and wider stakeholders must do more to alleviate the immense pressure our unpaid carers are under and ensure they have access to the breaks, services and financial support they need.



- 22 Carers NI (2023). The health and wellbeing impacts of unpaid caring in Northern Ireland: State of Caring survey 2023 policy briefing.
- 23 Carer Poverty Commission (2023). Experiences of poverty among unpaid carers in Northern Ireland.
- 24 Department for Communities (2022). Family Resources Survey 2021-22 Carers, careers and disability.
- 25 See: https://respitality.sharedcarescotland.org.uk.

### Carers NI is calling for a restored Stormont Assembly and Executive to:

- Develop a new, holistic and cross-departmental Carers Strategy for Northern Ireland, to act as a vehicle for the strategic policy change unpaid carers need, including the measures outlined below
- Legislate for a new legal right to breaks from unpaid caring, taking inspiration from the similar policy currently being introduced in Scotland
- Prioritise the expansion of community care packages and replacement care, including overnight sitting services, as part of the reform of adult social care. This will require progress on the key drivers of community care pressure, particularly workforce shortages
- Create a regional Carers' Register and a suite of new supports for carers on the register, including accessible information, training and advice to help them in their caring roles
- Create a local equivalent to Scotland's Respitality programme, which connects unpaid carers with hospitality, tourism and leisure businesses that donate free short breaks or respite opportunities
- Introduce a Carer's Allowance Supplement scheme to boost the value of Carer's Allowance
- Deliver root-and-branch reform of the Carer's Allowance system, including:
  - » Multiple payments for those caring for more than one person
  - » Expansion of the earnings threshold and the introduction of a taper, to allow unpaid carers to keep part of their Carer's Allowance as they earn more
  - Eligibility for unpaid carers in receipt of their State Pension
- Introduce a new Carer Essentials Payment, to help unpaid carers better afford the high and inescapable extra costs of caring for someone with an illness or disability
- Legislate for paid carer's leave from work and a dayone right to request flexible working for all unpaid carers.

### Carers NI is calling for Health and Social Care Trusts to:

- Fully restore day services, short break and respite provision to pre-pandemic levels as a key first step; then expand provision of these services to address the significant levels of pre-pandemic unmet need
- Ensure full compliance with the statutory obligation on Health and Social Care Trusts to offer Carer's Assessments or re-assessments to any carer who wants one
- Increase the number of Self-Directed Support (SDS) navigator roles in each Health Trust, to better support unpaid carers dealing with the complexity and bureaucracy of the SDS system
- Provide annual health MOTs for all unpaid carers, to proactively identify and address health issues among unpaid carers
- Provide funding packages for unpaid carer breaks, including holiday and hotel vouchers
- Improve forward planning and communication around respite and break availability, to allow unpaid carers to make meaningful plans when they have access to a break.

# Appendix A

### Table A.1: Nominal value of unpaid carers' contributions and real change in carers' contributions by Health and Social Care Trust in Northern Ireland, 2011 and 2021

Health and Social Care Trust (HSCT)	2021 No. of unpaid carers	2011 No. of unpaid carers	Nominal values 2021 (£m)	Nominal values 2011 (£m)	(%) Change 2021-2011
Belfast HSCT	42,252	42,913	1,223	690	52%
Northern HSCT	56,099	53,507	1,493	893	44%
South Eastern HSCT	46,095	44,460	1,072	659	40%
Southern HSCT	43,370	40,607	1,167	698	44%
Western HSCT	34,400	32,493	871	578	30%

Source: Authors' calculations based on the Census 2021 and Census 2011 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). The unit cost is the nominal value of unpaid carers' contributions (not adjusted for inflation). The percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH). HSCT: Health and Social Care Trust.

# Appendix B: Detailed methodology

# 1. Distributions of the hours of unpaid care

All our assumptions on the distributions of hours of unpaid care are based on survey evidence from the UK Household Longitudinal Study (calendar years 2020<sup>26</sup> and 2011<sup>27</sup>), also known as Understanding Society. As Understanding Society provides more granular information on the hours of care than the Census 2021/2011 (1 to 19 hours, 20 to 49 hours and 50 or more hours per week), it enabled us to obtain more specific and robust estimates for the hours of care<sup>28</sup>.

In the Understanding Society dataset, people were identified as (unpaid) carers if they answered 'yes' to either of the following questions:

- "Is there anyone living with you who is sick, disabled or elderly whom you look after or give special help to (for example, a sick, disabled or elderly relative, husband, wife or friend etc)?"
- "Do you provide some regular service or help for any sick, disabled or elderly person not living with you?"

Hours of care per week were identified by asking survey participants the following question:

- "Now thinking about everyone who you look after or provide help for, both those living with you and not living with you – in total, how many hours do you spend each week looking after or helping them?"
  - » "0-4 hours per week"
  - » "5-9 hours per week"
  - » "10-19 hours per week"
  - » "20-34 hours per week"
  - » "35-49" hours per week"
  - » "50-99 hours per week"
  - » "100 or more hours per week/continuous care"
  - » "Varies under 20"
  - » "Varies 20 hours or more"

Specifically, the distribution of hours of care estimated using the Understanding Society dataset are as follows:

### 2021

- 68,690 unpaid carers provided 50 or more hours of care per week. We have assumed that these unpaid carers were all providing 50 hours of care per week. This is likely an underestimate
- 52,743 unpaid carers provided 20-49 hours of care per week. Here we have assumed that 58% (30,591) of unpaid carers were providing, on average, 27 hours of care each week and 42% (22,152) 42 hours of care per week
- 100,783 unpaid carers provided 1-19 hours of care per week. We have assumed that 56% (56,438) of this group were caring for 2 hours per week, 25% (25,196) for 7 hours per week, and 19% (19,149) for 15 hours per week.

#### 2011

- 56,310 unpaid carers provided 50 or more hours of care per week. We have assumed that these unpaid carers were all providing 50 hours of care per week. This is likely an underestimate
- 35,369 unpaid carers provided 20-49 hours of care per week. Here we have assumed that 66% (23,380) of unpaid carers were providing, on average, 27 hours of care each week and 34% (11,989) 42 hours of care per week
- 122,301 unpaid carers provided 1-19 hours of care per week. We have assumed that 47% (57,005) of this group were caring for 2 hours per week, 27% (33,166) for 7 hours per week, and 26% (32,130) for 15 hours per week.

<sup>26</sup> University of Essex, Institute for Social and Economic Research. (2022). Understanding Society: Waves 1-11, 2010-2020: Waves 1-18, 1991-2009. [data collection]. 16th Edition. UK Data Service. SN: 6614, <u>http://doi.org/10.5255/UKDA-SN-6614-17</u>.

<sup>27</sup> University of Essex, Institute for Social and Economic Research. (2022). Understanding Society: Waves 1-11, 2010-2020: Waves 1-18, 1991-2009. [data collection]. 16th Edition. UK Data Service. SN: 6614, <u>http://doi.org/10.5255/UKDA-SN-6614-17</u>.

<sup>28</sup> Census 2021 breaks down the 20 to 49 hours of care into narrower categories (20 to 34 hours, 35 to 49 hours). This was not the case for Census 2011. Therefore, to obtain more consistent estimates for the differences in the total value of unpaid care between Census 2021 and 2011, this report uses the distribution computed using Understanding Society data to estimate the hours of care in both 2021 and 2011.

### 2. Age standardisation

Age-standardised proportions were used to compute the proportion of unpaid carers. Age-standardisation is a crucial step when making comparisons between populations over time, as the age composition of a population at any given time affects the proportion of unpaid carers within that population. Compared with crude percentages, the age-standardised proportions have the advantage of mitigating the impact of population ageing. This ensures a more accurate comparison of actual changes over time and thus renders them a more suitable and reliable measure.

One method for calculating the age-standardised proportions is adjusting two populations mathematically to have the same age structure as a third reference population, known as the standard population. In this report, the 2013 European Standard Population (ESP) – which has become an accepted methodological standard in health statistics in the UK and the rest of Europe – was used as the standard population. As the NISRA does not provide age-standardised proportions, the authors derived them using a methodology consistent with the guidelines offered by the Office for National Statistics (ONS).<sup>29</sup>

### **Robustness checks**

### 1. Real value versus nominal value

Table B.1 shows the value of unpaid carer's contributions in Northern Ireland in real terms (inflation adjusted).After adjusting for inflation, the cost of replacement care for Belfast, Northern, South Eastern, Southern and Western HSCT are £19.50, £18.30, £16.40, £18.40, and £16.50 respectively in 2021. In 2011, the inflation-adjusted unit costs are £14.30, £15.80, £14.30, £15.70, and £15.60 per hour respectively. After adjusting for inflation, the real value of unpaid carer's contributions in Northern Ireland in 2021 was £5.4 billion, representing a £1.6 billion increase from 2011.

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	(%) Change 2021-2011
19 hours or less	100,783	122,301	533	651	-18.2%
20 to 49 hours	52,743	35,369	1,631	893	82.6%
50 hrs or more	68,690	56,310	3,186	2,215	43.8%
Total	222,216	213,980	5,350	3,760	42.3%

#### Table B.1: Change in the real value of unpaid carers' contributions in Northern Ireland, 2011 and 2021

Source: Authors' calculations based on Census 2011 and 2021 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). The unit cost considered is adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH) Hence, Columns 'Value 2021', 'Value 2011' and '(%) Change 2021-2011' represent the real value of unpaid carers' contributions (adjusted for inflation).

According to Table B.1 in Northern Ireland, carers' contributions to the care of others in 2021 are about:

- £5.4 billion per year
- £102.9 million per week
- £14.7 million per day
- £0.6 million per hour.

29 All the technical details can be found at the official website of the ONS: https://webarchive.nationalarchives.gov.uk/ukgwa/20160106020035/http://www.ons.gov. uk/ons/guide-method/user-guidance/health-and-life-events/revised-european-standard-population-2013--2013-esp-/index.html

### 2. Disaggregation of the 50+ category

The estimated value of unpaid care presented in Table 2 is a conservative estimate. This is because there is a lack of information on how the number of hours was distributed among those who provided 50 or more hours of care. Therefore, people who provided 50 or more hours of care were all assumed to provide precisely 50 hours of care (they are likely providing more hours of unpaid care). To further approximate the actual distribution of the number of hours, this section presents the result of a robustness check using UK Household Longitudinal Study Data (see Appendix B.1), which enables us to distinguish carers who provided '50 to 99' hours of care per week. More specifically:

#### 2021

#### 2011

- 68,690 unpaid carers provided 50 or more hours of care per week. We have assumed that of those unpaid carers, 26% were providing 50 to 99 hours and 74% 100+ hours of care per week.
- 56,310 unpaid carers provided 50 or more hours of care per week. We have assumed that of those unpaid carers, 29% were providing 50 to 99 hours and 71% 100+ hours of care per week.

### Table B.2: Nominal value of unpaid carers' contributions and real change in the value of unpaid carers' contributions in Northern Ireland with the disaggregation of the 50+ category, 2011 and 2021

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	(%) Change 2021-2011
19 hours or less	100,783	122,301	580	610	-18.2%
20 to 49 hours	52,743	35,369	1,776	836	82.6%
50 hrs or more	68,690	56,310	6,030	3,604	43.8%
Total	222,216	213,980	8,387	5,050	42.8%

Source: Authors' calculations based on the Census 2011 and 2021 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). Columns 'Value 2021' and 'Value 2011' represent the nominal value of unpaid carers' contributions (not adjusted for inflation). The percentage change in unpaid carers' contributions (% change 2021-2011) considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH).

According to Table B.2 in Northern Ireland, carers' contributions to the care of others in 2021 are about:

- £8.4 billion per year
- £161.3 million per week
- £23.0 million per day
- £1.0 million per hour.

### 3. Removing younger carers aged 5-17 from the analysis

In this report, the proportion of unpaid carers and the value of care were calculated based on the entire population of people aged 5 years and above. To understand the contribution of adult unpaid carers only, we conducted the same analysis separating the values contributed by adults (aged 18 years and above) from those provided by younger carers. Table B.3 shows the number and proportion of adult unpaid carers and younger unpaid carers by hours of care. It suggests that although the majority of unpaid carers were adults, there were still 5,326 younger unpaid carers in 2021. However, it is important to note that the number and proportion of younger carers has decreased since 2011. Additionally, adult carers tend to provide more intensive care (20 or more hours) than younger carers.

#### Table B.3: Total number of adult and younger unpaid carers in Northern Ireland, 2011 and 2021

	2021 No. of unpaid carers	2021 (%)*	2011 No. of unpaid carers	2011 (%)*
Northern Ireland total				
19 hours or less	100,783	5.7%	122,301	7.4%
20 to 49 hours	52,743	3.0%	35,369	2.2%
50 hrs or more	68,690	4.0%	56,310	3.6%
Total	222,216	12.8%	213,980	13.2%
Adult carers				
19 hours or less	96,875	6.5%	115,604	8.3%
20 to 49 hours	51,914	3.5%	34,413	2.5%
50 hrs or more	68,101	4.7%	55,490	4.2%
Total	216,890	14.7%	205,507	15.1%
Younger Carers				
19 hours or less	3,908	1.2%	6,697	2.1%
20 to 49 hours	829	0.3%	956	0.3%
50 hrs or more	589	0.2%	820	0.3%
Total	5,326	1.7%	8,473	2.6%

Source: Authors' calculations based on the Census 2011 and 2021 in Northern Ireland (NISRA). Note: \* indicates age-standardised proportion (authors' calculation).

Table B.4 shows the change in the economic value of unpaid carers' contributions after excluding younger carers. As the increase in the number of unpaid carers was mainly attributed to adult carers, the percentage change in the economic value of unpaid carers (44.4%) is even higher than the figure for the monetary value of care which includes the younger carers.

### Table B.4: Nominal value of unpaid carers' contributions and real change in the value of unpaid carers' contributions in Northern Ireland (adult population), 2011 and 2021

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	Change 2021-2011 (%)
19 hours or less	96,875	115,604	558	574	-16.5%
20 to 49 hours	51,914	34,413	1,749	810	85.6%
50 hrs or more	68,101	55,490	3,440	2,035	45.3%
Total	216,890	205,507	5,746	3,419	44.4%

Source: Authors' calculations based on the Census 2011 and 2021 (adult population) in Northern Ireland (NISRA) using the unit cost of replacement care as determined by Community Service Indicators (Department of Health, NI, 2011; 2020). Columns 'Value 2021' and 'Value 2011' represent the nominal value of unpaid carers' contributions (not adjusted for inflation). The percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH). The value of unpaid care (adult population) in 2021 was calculated based on the HSCT-specific unit costs and number of carers. However, the HSCT-specific number of adult unpaid carers is not published by the NISRA. Therefore, to calculate the value of unpaid care (adult population) in 2011, we used the average unit cost of domiciliary care in Northern Ireland in 2011 across five HSCTs, which was then multiplied by the total number of unpaid care hours contributed by all unpaid carers in Northern Ireland.

According to Table B.4 in Northern Ireland, adult unpaid carers' contributions to the care of others in 2021 are approximately:

- £5.7 billion per year
- £110.5 million per week
- £15.7 million per day
- £0.7 million per hour.

This means that out of the £5.8 billion per year, **£80 million per year** is the value of care provided by young carers (aged 5 to 17 years).

### 4. Estimating the unit cost of domiciliary care in Northern Ireland in 2021

At the time of writing, as the unit cost of domiciliary care in Northern Ireland in 2021 was not produced by the Department of Health (Northern Ireland), we used the unit cost in 2019/20 to compute the value of care in 2021. It is essential to acknowledge that this approach likely represents a conservative estimate for the unit cost in 2021. Given the historical trend of increasing costs in adult social care in Northern Ireland, employing the 2019/20 unit cost is likely to underestimate the actual value of unpaid care in this report. To account for the temporal trends of the unit cost, we conducted a time series analysis to forecast the unit cost in 2021 based on the historical data available (from 2006/07 to 2019/20). Results show that the unit costs for Belfast, Northern, South Eastern, Southern and Western HSCT in 2021 were estimated to be £22.60, £20.80, £18.80, £21.20, and £18.00<sup>30</sup> per hour respectively.

Table B.5 shows the value of unpaid carer's contributions in Northern Ireland in real terms using the predicted unit cost of domiciliary care in 2021.

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	Change 2021-2011 (%)
19 hours or less	100,783	122,301	609	610	-16.2%
20 to 49 hours	52,743	35,369	1,864	836	86.9%
50 hrs or more	68,690	56,310	3,640	2,073	47.2%
Total	222,216	213,980	6,113	3,519	45.7%

### Table B.5: Nominal value of unpaid carers' contributions and real change in the value of unpaid carers' contributions in Northern Ireland using the predicted unit cost in 2021

Source: Authors' calculations based on the Census 2011 and 2021 in Northern Ireland (NISRA) using the unit cost obtained from Community Service Indicators (Department of Health, NI, 2011) and author's own estimation based on historical unit costs from 2006/07 to 2019/20 in Northern Ireland. Columns 'Value 2021' and 'Value 2011' represent the nominal value of unpaid carers' contributions (which is not adjusted for inflation). The percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH).

> According to Table B.5, in Northern Ireland, adult unpaid carers' contributions to the care of others in 2021 are approximately:

- £6.1 billion per year
- £117.6 million per week
- £16.7 million per day
- £0.7 million per hour.

30 The predicted unit costs in 2021 are expressed in nominal terms, and not adjusted for inflation.

### 5. Using the PSSRU unit cost of domiciliary care

Another reliable source for determining the unit cost of domiciliary care is the estimation provided by the Personal Social Services Research Unit (PSSRU)<sup>31,32</sup>. The PSSRU has consistently estimated unit costs for health and social care on an annual basis since 1992. These PSSRU estimates are used in academic research and policy development. While it's worth noting that PSSRU unit costs are primarily based on data from England, and may not be specific to Northern Ireland, they still serve a valuable purpose in facilitating cross-jurisdiction comparisons of the value of unpaid care across the UK.

Table B.6 presents the value of unpaid care calculated using the PSSRU unit costs.

### Table B.6: Nominal value of unpaid carers' contributions and real change in the value of unpaid carers' contributions in Northern Ireland using the PSSRU unit cost, 2011 and 2021

	2021 No. of unpaid carers	2011 No. of unpaid carers	Value 2021 (£m)	Value 2011 (£m)	Change 2021-2011 (%)
19 hours or less	100,783	122,301	747	775	-19.1%
20 to 49 hours	52,743	35,369	2,283	1,062	80.6%
50 hrs or more	68,690	56,310	4,465	2,635	42.3%
Total	222,216	213,980	7,495	4,473	40.8%

Source: Authors' calculations based on the Census 2011 and 2021 in Northern Ireland (NISRA) using the unit cost of replacement care as determined by the Personal Social Services Research Unit (Curtis, 2011; Jones and Burns, 2021). Columns 'Value 2021' and 'Value 2011' represent the nominal value of unpaid carers' contributions (which is not adjusted for inflation) to provide discrete estimates for the value of unpaid care in 2021 and 2011. However, to enable comparisons in the value of unpaid care between 2011 and 2021, the percentage change in unpaid carers' contributions considers the real unit cost, adjusted for inflation using the Consumer Prices Index including owner occupiers' housing cost (CPIH).

31 Jones, K. & Burns, A. (2021). Unit Costs of Health and Social Care 2021, Personal Social Services Research Unit, University of Kent, Canterbury.
 32 Curtis, L. (2011). Unit Costs of Health and Social Care 2011, Personal Social Services Research Unit, University of Kent, Canterbury.

# Contact

### 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 ESRC (Economic & Social Research Council), 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 Sue Yeandle 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.

### O Centre for Care

T 0114 222 8369 E centreforcare@sheffield.ac.uk

centreforcare.ac.uk

### Carers NI

Carers NI is Northern Ireland's membership body for unpaid carers. We're here to listen, to give carers expert information and tailored advice. We champion the rights of Northern Ireland's 220,000 carers and support them in finding new ways to manage at home, at work, or in their community. We're here to make life better for carers.



E info@carersni.org

carersuk.org/NI



Carers NI E info@carersni.org carersuk.org/NI



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