Senedd Cymru/Welsh Parliament - Health and Social Care Committee

Centre for Care response to: Improving access to support for unpaid carers inquiry

This response is provided by members of the ESRC-funded Centre for Care and IMProving Adult Care Together (IMPACT) Centre, alongside collaborators from Swansea and Cardiff Universities. 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, as one of its flagship research centres, with contributions from the National Institute for Health Research (NIHR) and Department of Health and Social Care, 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. It also draws on evidence from the IMProving Adult Care Together (IMPACT) Centre, funded by the ESRC and the Health Foundation, principally from the IMPACT Network on Carers, Transitions and Co-production and research from Dr Maria Cheshire Allen and Dr Dan Burrows from the Swansea and Cardiff Universities respectively.

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Introduction

1. Unpaid or informal carers are those who support family, friends, neighbours, who have difficulties related to disabilities, long-term illnesses, and/or older-age (Petrillo, 2024).
2. It's been estimated that there are up to 12 million unpaid carers in the UK (Watkins and Overton, 2024). There is an observed increase in the amount of carers providing high intensity care, that being up to and over 50 hours of care per week (Petrillo and Bennett, 2023) - in Wales, between 2011 and 2021, the percentage of carers providing 50 or more hours of care a week rose by 20.1% (Petrillo et al., 2024).
3. Research has been undertaken to estimate the monetary value of unpaid care. This is to demonstrate the incredible social value of unpaid carers and their economic contribution to society, while often not receiving adequate financial support (Petrillo and Bennett, 2023). The value of care provided by unpaid carers across the UK is £184bn (Petrillo et al, 2024). This is four times the expenditure of adult social care services that are publicly funded (Petrillio et al, 2024). In Wales, the value of care provided by unpaid carers is £10.8bn (Petrillio et al, 2024), more than the expenditure for the NHS in 2023/4 (£9.2bn, Welsh Government, 2024).
4. Unpaid carers often face multiple challenges as a result of their caring responsibilities. A breadth of evidence suggests that unpaid carers face financial difficulty, with negative effects on their employment and income. Unpaid carers are more likely to suffer from ill health and be forced into early retirement on account of their caring responsibilities (Watkins and Overton, 2024).

'Barriers faced by unpaid carers in Wales'

A case for tackling health and deprivation inequalities

5. Addressing deeper structural inequalities present in Wales is a route to in turn address barriers or challenges faced by unpaid carers. Prevalent deprivation in Wales and the consequences of this as negatively impacting health outcomes impacts the experiences of unpaid carers and those being cared for.
6. As a devolved nation with significant legislative powers since 1999, Wales faces distinctive demographic and health pressures. Research by the National Public Health Service for Wales looked into the link between deprivation indicators and instances of poor health, which show that in almost all cases, people living in the

most deprived areas of Wales have worse health indicators than those in wealthier areas (National Public Health Service for Wales, 2004).

7. The country has the largest proportion of older people among UK nations, the lowest disability-free life expectancy across all four nations, and disproportionately higher disability rates and limiting long-term conditions across all age groups (McKee et al., 2021). In addition, Wales has a significantly higher proportion of people providing intensive unpaid care (50+ hours weekly) and greater population concentration in deprived areas with associated health challenges. Research from England also suggests that an increasing number of unpaid carers who provide care, are themselves disabled (Edwards and Loughnane, 2024). This intersection of people are particularly vulnerable if faced with compounding issues of financial security.
8. All of these factors result in increased pressure on social care and NHS services which are increasingly unable to meet the demands of people requiring treatment and care. Research suggests that an increased concentration on health promotion, disease prevention and the alleviation of poverty to be vital in alleviating pressure on public services and subsequently unpaid carers, who bear the burden of meeting care needs that cannot be provided for by the state (Mckee et al, 2021; Carers UK, 2024).
9. There has been some legislative progress in Wales to improve the conditions of social care services. The Welsh Government has implemented the world-leading Well-being of Future Generations (Wales) Act 2015 and the Social Services and Wellbeing (Wales) Act 2014 the central legislative framework for health and care. Across the 4 nations, Wales has seen the biggest increase in spending in support for older people, with a 17% increase in real terms since 2020/21 (Nuffield Trust, 2023).
10. Despite these progressive policy frameworks, The Welsh Government commissioned a comprehensive independent evaluation (2018-2022) of the implementation of the Social Services and Well-being Act, and was led by academics across four Welsh universities. The findings reveal significant implementation challenges linked to underlying structural, financial or capacity pressures. The process evaluation sets out a view from the workforce that statutory care services are reactive and a last resort and not early intervention oriented, with comments that the threshold for support is too high (Llewellyn et al., 2023).
11. Furthermore, qualitative research indicates that unpaid carers continue to report significant unmet needs and strain (Cheshire-Allen & Calder, 2022), highlighting the persistent gap between policy ambition and lived experiences of care provision.

12. **Recommendation 1 -** There is a need to address systemic deprivation in Wales to improve health outcomes for unpaid carers and those who are cared for.
13. **Recommendation 2 -** Policy intervention and legislative change must consider the contextual capacity and financial restraints of implementation specific to Wales in order to deliver a better service for unpaid carers.

'Barriers faced by unpaid carers in Wales'

Leveraging Data to Understand Carers Across Wales: The Unpaid Care Dashboard

14. At the Centre for Care, researchers found that important stakeholders and people with lived experience did not have easily accessible information on the demography of unpaid carers across the UK.
15. Maria Petrillo, Matt Bennett and Thomas Siddall worked collaboratively with local authority and charity partners to build the The Unpaid Care Dashboard, an interactive tool that uses 2011 and 2021 Census data to allow the user to explore demographic information around unpaid carers across local authorities in the UK, to create charts, graphs and reports with this data.
16. The user can examine how unpaid carers have changed over time - how much care they may provide, their health and types of employment. The user can also compare data across different local authorities, age, hours of care etc (Petrillo et al, 2025).
17. The Dashboard covers all four countries in the UK, including Wales. This means that localised support services and Welsh parliament can utilise this tool to better understand the demography across Welsh regions. This dashboard can provide as a useful tool to understand the breakdown of unpaid carers across metrics such as age, gender, health, employment etc to enable further investigation into potential barriers faced by different demographic groups in accessing support.
18. Nationally, the Dashboard shows the total number of unpaid carers in Wales across the 23 Local Authorities, the proportion who are disabled (31%), economically inactive (49%), and are older (aged 55-65- 36.4% and 65+- 25.7%).
19. Local authorities and care services can use this tool to better understand how to support unpaid carers by examining patterns of care and adjusting resources to better support local populations (Petrillo et al, 2025).
20. An example of the way this could be used in the Welsh context is provided in **Annex A** - screenshot 1 shows all local regions pertaining to Unpaid Care statistics - demography, value of care provided, hours of care provided, age, ethnicity, marital

status and disability information. This is compared with the same data for Cardiff in screenshot 2.

21. Screenshot 3 utilises the 'compare' tool in the Dashboard, where the user can compare metrics of unpaid carers across two localities (the user can also compare age, hours of care etc). In this example, Cardiff and Swansea have been compared on the Demography data option.
22. It is also possible to select multiple localities to create a picture of caring across Wales, and also across time, comparing data from the 2011 and 2021 Censuses.
23. The Centre for Care would be happy to support the Welsh Governments' inquiry to use of the Unpaid Care Dashboard by giving tutorials and answering any further questions on how best to utilise the tool, do not hesitate to contact us.
24. **Recommendation 3:** Leverage tools like the Unpaid Care Dashboard to develop policy, strategy and practice informed by data insights into local carer populations across Wales. For example, the Dashboard's ability to compare 2011 and 2021 Census data could be used to analyse trends in unpaid care. This would allow Local Authorities to anticipate future needs and proactively adjust services, rather than reactively responding to issues- i.e. if data shows an increase in the number of carers in a particular age bracket, services for that group could be enhanced in advance. The Dashboard's comparison feature could also be used by Local Authorities to share best practices and insights across areas with similar caring populations and therefore common challenges.

'Barriers faced by unpaid carers in Wales, improvements to the Social Services and Well-being Act (Wales) and improvements to respite care'

The IMPACT Network

25. IMPACT Networks bring together academics, people who draw on care and support and practice partners interested in implementing practical improvements in adult social care drawing on evidence from the sector (IMPACT, 2025a).
26. As part of the IMPACT network on 'Carers, Transition and Coproduction' - Swansea University (Dr Maria Cheshire-Allen and Dr Aelwyn Williams) coordinated a Network in Wales, attended by a mix of unpaid carers, academics, representatives from local authorities and third sector organizations.
27. The insights provide useful evidence for the barriers faced by unpaid carers in Wales, albeit in a specific region, and recommendations for potential policy interventions to

improve service which would be bolstered by examining local perspectives of unpaid carers across Wales to compare and contrast experiences.

Case Study: Barriers for Unpaid Carers in Swansea - 'Support, transitions and power'

28. Carers in Swansea University Network often felt the support offered to them was not consistent in transition periods. These could be between service providers, phases of care and notably between health and social care systems (IMPACT, 2025b).
29. The impact of this lack of consistency would also result in carers feeling they had to "retell their story" to each professional they encountered (IMPACT, 2025b). This results in an emotional toll being placed on the carer, where the repetition of this process makes them feel unsupported, emotionally burnt out and invisible during important moments in their lives (IMPACT, 2025b).
30. Participants spoke of a 'power imbalance' between professionals and carers during assessments where carers felt professionals made assumptions about their needs or those receiving care rather than working with them as equals in an empowering way (IMPACT, 2025b).
31. **Recommendation 4:** Participants discussed integrating storytelling into their care records, such as 'digital postcards' sharing their experiences in order to improve the relationship between professional support and the carers through empathy. Further research to understand how to balance standardization and personal narrative while improving this relationship would be beneficial.

Social Services and Well-being Act (Wales) 2014

32. The Social Services and Wellbeing Act emphasises person centred approaches and co-production. The participants at Swansea University felt these aims were not being fulfilled in practice, considering they felt disempowered and unimportant during key transition periods in the care system and were not actively involved in decision making processes for their support or for those they cared for (IMPACT, 2025b).
33. A participant was quoted - ***"Carers need to feel that they are visible, a valued part of the changes that happen. At the moment, it doesn't feel as if co-production is being taken seriously because authorities are still afraid of letting go of control, maybe sometimes purely because they are also being overworked and are also subject to the control of e.g. their own unrealistic targets." (IMPACT, 2025b).***
34. **Recommendation 5:** The Social Services and Wellbeing (Wales) Act is an

opportunity to truly integrate carer-led co-production with a stronger implementation framework, to ensure its intentions are met in practice and active monitoring of this implementation.

Gaps in provision for young people aged 16-25

35. Some participants at the Swansea University Network noted that for young people (between ages 16-25) moving from a young carers service to an adult carers service there was insufficient provision (IMPACT, 2025b). This was also reported in cases that young people were moving into further or higher education or employment.
36. Providers discussed how challenging it can be to support young carers across their interactions with health, education and universities. It was acknowledged by providers that this gap in support was widespread with two organisations across Wales able to meet the needs of this age group (IMPACT, 2025b).

Lack of integration across information systems

37. Providers noted that supporting carers through transitions in healthcare was impeded by information systems across health and social care not being well integrated (IMPACT, 2025b). The providers noted that accessing relevant healthcare information on different platforms was difficult and impeded their work (IMPACT, 2025b).

Respite services

38. Participants identified that 'respite services' could mean a broad range of different services but that professionals they were engaged with had rigid and inflexible notions of what this might mean to an individual carer (IMPACT, 2025b). This could create a difficulty in assessing how accessible respite services are within the confines of a 'professional' definition, rather than one defined by carers.
39. **Recommendation 6:** Reconsider the existing 'professional' definitions of respite care to centre the experiences of carers and their perception of respite.

Financial pressures and vulnerability

40. Participants felt concerned about financial pressures through transition periods - carers were concerned about their finances and their ability to maintain independence when entering retirement with caring responsibilities. Participants also felt concerned when transitioning from young carers to adult carers and the financial strain if there is a gap in provision (IMPACT, 2025b).
41. Providers emphasised the importance of working closely with carers to understand

their experience in order to co-produce services, however this was considered to be challenging in reality due to financial constraints (IMPACT, 2025b).

Conclusion

42. Our evidence highlights several key issues related to support for unpaid carers in Wales. These include a lack of consistent support during transitions, feelings of disempowerment and invisibility, narrow definitions of 'respite', and significant gaps in provision for young carers and those facing financial hardship.
43. Our recommendations aim to address these issues by advocating for a stronger implementation of the Social Services and Well-being Act 2014 (Wales), leveraging the tools such as the Unpaid Care Dashboard to support data-driven policy and service design, and reimagining definitions of care to be more flexible and person-centered, drawing on insights from lived experience. By integrating these recommendations, policy and service design can move towards a more proactive, consistent, and empowering model of support for unpaid carers across Wales.

Recommendations:

Overarching considerations -

44. Prioritise addressing systemic deprivation in Wales to improve health outcomes for unpaid carers and those who are cared for.
45. Policy intervention and legislative change must consider the contextual capacity and financial restraints of implementation specific to Wales in order to deliver a better service for unpaid carers.

Specific changes -

46. Leverage tools like the Unpaid Care Dashboard to develop policy, strategy and practice informed by data insights into local carer populations across Wales.
47. The Social Services and Wellbeing (Wales) Act should utilise the opportunity to truly integrate carer-led co-production with a stronger implementation framework, to ensure its intentions are met in practice and active monitoring of this implementation.
48. Reconsider the existing 'professional' definitions of respite care to centre the experiences of carers and their perception of respite.

49. Focus on improving the relationship between carers and professional care service staff, where appropriate, consider integrating storytelling tools for carers, using their experiences to improve professional understanding of their lived experience.

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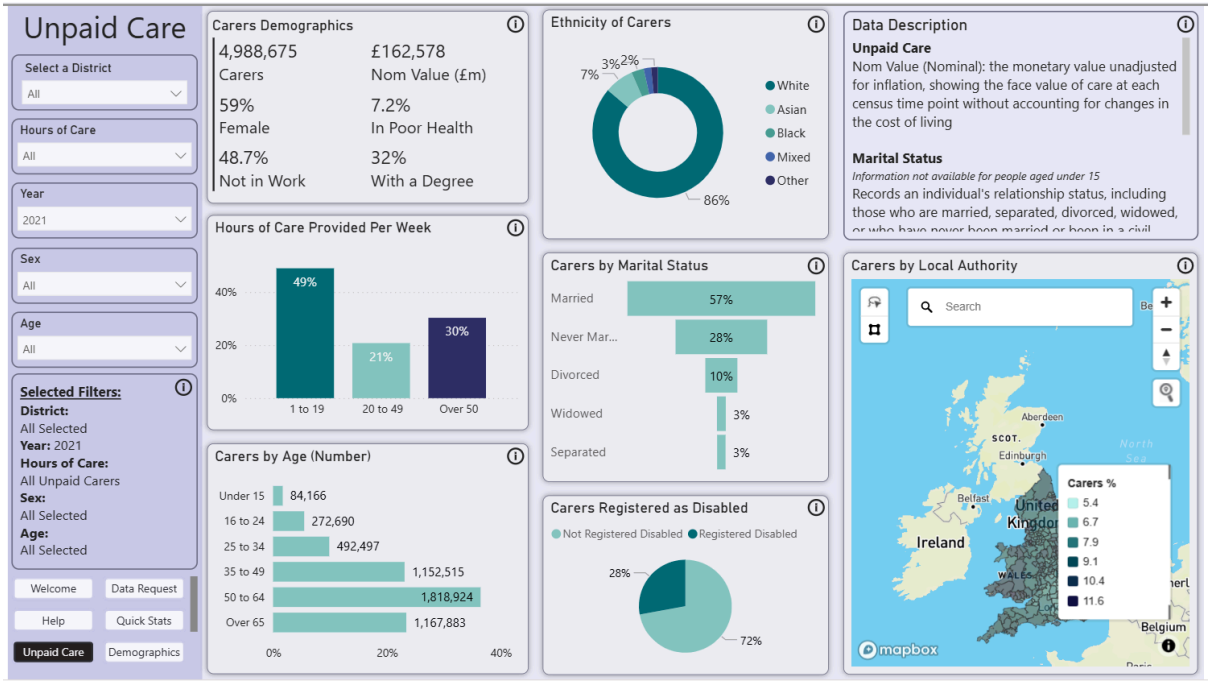
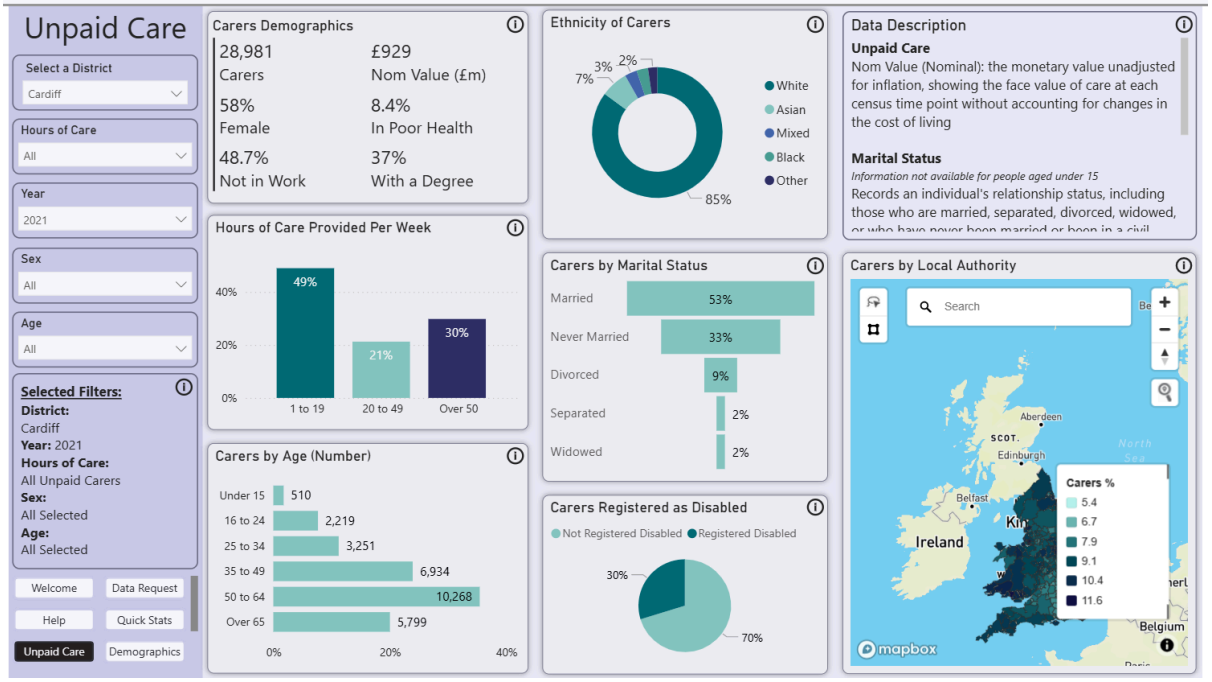
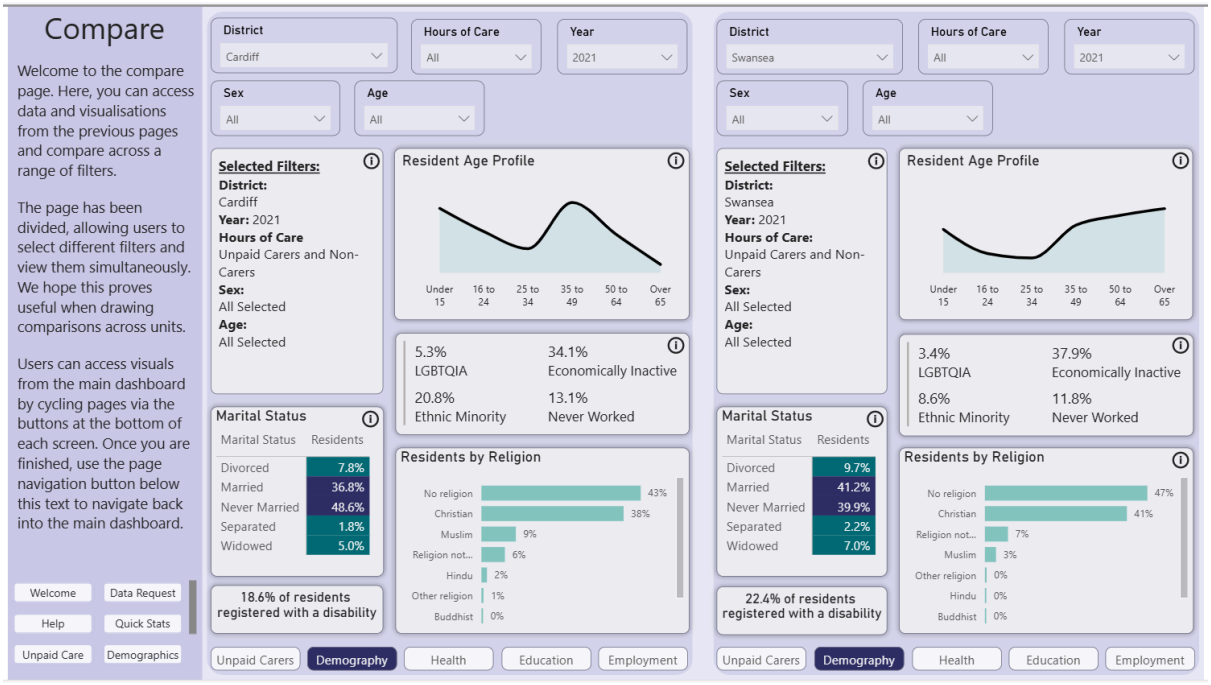
Annex A - Unpaid Care Dashboard screenshots

Screenshot 1 -



Screenshot 2 -



Screenshot 3 -