

Appendix 1 - Review data

1. The [2021 Census](#) found that there are 310,751 carers in Wales, representing 10% of the population. Whilst this figure was lower than in 2011, the Census found that the remaining carers were providing more hours of care; it found that 107,000 people in Wales provided 50 or more hours of unpaid care a week. The local authority with the highest proportion of people who provided any amount of unpaid care in Wales was Neath Port Talbot (12.3%), which also reported the joint highest proportion of disabled people. Neath Port Talbot also had the highest proportion of people who provided 50 or more hours of unpaid care a week (4.5%) and people who provided 20 to 49 hours of unpaid care a week (2.9%).
2. In 2021, in Wales, the age range of the highest percentage of unpaid carers was individuals aged between 55 and 59 years for females and between 55 and 64 years for males. The older age groups provided the highest number of hours of unpaid care.
3. According to the 2011 Census, there were [9,076 Black, Asian or minority ethnic carers in Wales](#). This represented 2.5% of all carers in Wales. There were also approximately 320 unpaid carers who were from 'Gypsy or Irish Traveller' communities. This represented 0.09% of the unpaid carer population. There is no data to identify the number of carers whose language of choice is Welsh.
4. [Local authority data](#) suggests that many carers are not having their needs assessed or receiving the support needed. Of those that are invited for an assessment, just under 50% refuse that assessment.
5. The National Assembly for Wales published its '[Caring for our future](#)' report in 2019. The report noted that, without unpaid carers, the social care system would face collapse. It reported that many felt desperate, undervalued and that they were treated with little respect. It noted that the work undertaken by unpaid carers represents huge cost savings to the state and, as such, providing appropriate support was a significant area of preventative spend.
6. Carers Wales, an organisation representing carers in Wales, published its '[Track the Act Briefing 5](#)' in 2020, as part of its annual programme monitoring the implementation of the Social Services and Well-being Act 2014. It found that 85% of 620 respondents from

across all 22 local authorities had not had a carer's needs assessment in the year before March 2020; 41% had not heard of a carer's needs assessment before completing their survey and only 10% of carers had received information or advice services from local authorities.

7. The [Caring \(National Survey for Wales\)](#), published by Welsh Government in March 2021, found that people between the ages of 45 and 74 were the age group most likely to be carers. It also found that people living in social housing were more likely to be carers than owner-occupiers and people living in the most deprived 20% of areas were more likely to be carers than those living in the 20% least deprived areas. In contrast to the data collected by StatsWales, in which it was found that as many as 50% of carers turn down assessments, only 8 % of carers in this survey turned down an assessment, with many of those responding stating that they did so as they did not see the value of it.

8. In March 2021, Welsh Government launched its [Strategy for unpaid carers](#). The strategy outlined what Welsh Government will do to improve the recognition of and support of carers. It recognised that early intervention and prevention was critical and that there was a need to embed the preventative aspects of the SSWB Act more effectively in public services and move key providers of services, including the third sector, towards an improved model of support for unpaid carers. It said that, if it failed to address those key issues, more unpaid carers and the people they care for, would reach crisis point before accessing vital support. It said that this, in turn, would increase the pressure on NHS and Social Services. The strategy identified 4 priorities: to identify and value unpaid carers, to provide information, advice and assistance, to support life alongside caring and to support carers in education and the workplace. The Welsh Government outlined the action to be taken to address the priorities in its [Strategy for unpaid carers: delivery plan 2021](#).

9. A [report](#) published by the Social Care Institute for Excellence for Social Care Wales in June 2021 identified barriers and enablers to accessing carers' needs assessments in Wales. The barriers included a lack of information, delays in accessing assessments and no definitive prescribed timescale to complete the assessment process. It also identified that some groups were more at risk of not accessing information, for example, those caring for children with additional support needs, young carers and carers of people living with dementia, those with language barriers, sensory impairments and limited internet access. The report also identified that carers in rural areas may have specific problems with social isolation, poverty, lack of transport and inaccessibility, making it more difficult to identify and support people who may need help with their caring roles.

10. Care Inspectorate Wales' [National Overview Report Assurance Checks of Children and Adult Social Services](#) (reviewed between September 2020 and July 2021) highlighted inconsistencies in carers being routinely offered assessments and the quality of assessments completed. It said that, when assessments were completed, the processes for communicating outcomes to carers required improvement. CIW found that there was evidence that practitioners would benefit from further training in relation to identifying eligibility and undertaking assessments for carers. It said that the need for further development was recognised by local authorities to improve engagement with carers and consistently offer assessments. CIW also identified that the capacity of services was insufficient to keep up with demand, outlining that, at that time, people's care and support needs were, at times, unmet, resulting in increased pressure on unpaid carers.

11. In [Caerphilly County Borough Council](#), CIW found evidence that carers' needs were being appropriately considered and supported alongside the cared for person, with their needs being assessed and documented separately to those of the cared for person. In [Ceredigion County Council](#) and [Flintshire County Council](#), CIW found evidence of carers being given the opportunity to tailor and manage their own support through the use of Direct Payments. It found that carers in Ceredigion valued the information and support provided by the Carers Unit. In Flintshire County Council, CIW also found evidence of carers' needs, including young carers, being appropriately considered and supported alongside the cared for person.

12. A [report](#) published by the Carers Trust in November 2022 found that, in a UK-wide survey, 46% of unpaid carers said that they had not had an assessment of their needs as an unpaid carer in the last year. Of those who had not had an assessment in the last year, 68% said they had not been offered one. 71% of the respondents who lived in Wales and had not had an assessment in the last year, said that they had not been offered one. Carers Trust told us that access to assessments had improved since its previous survey, which took place during the COVID-19 lockdown period. However, it said that there was still a concern that not enough unpaid carers were having their needs assessed, as local authorities were over-stretched.

13. A Report on Age Cymru's 2022 [Older Carers Survey](#) found that only 54% of carers were aware of their entitlement to a Carer's Needs Assessment from their local authority, making it clear that, although all carers should be aware of this right, many are not. It

found that there was a lack of consistency across local authorities in relation to carers' awareness of their right to an assessment, suggesting there needed to be a focus across Wales to make people aware of their right.

14. Carers Wales' ['State of Caring in Wales 2022'](#) report found that too many carers face barriers to receiving a carer's needs assessment, with many who are assessed feeling that the assessment did not sufficiently consider their needs or lead to meaningful support. The report highlighted that many carers find that, due to their caring role, their relationships are impacted, they often struggle to balance work and care and that they are facing their own physical and mental health problems as a result of their caring role. It said that carers often use their income or savings to pay for support services and care equipment and that they faced unprecedented pressure on their finances with the cost of living crisis.

15. Audit Wales' April 2022 report, [Direct Payments for Adult Social Care](#) found that there are inconsistencies in the way Direct Payments are promoted and managed by local authorities, meaning that services are not always equitable.

16. In March 2023, the Welsh Government published its ['From Act to Impact?'](#) report, following its evaluation of the Social Services and Well-Being (Wales) Act 2014 which focussed on the implementation of the SSWB Act rather than the way in which local services were being delivered. It noted that, despite the number of carers' needs assessments increasing year on year between 2016 and 2019, a decrease was noted in 2020/2021.

17. The [Evaluation of the Social Services and Well-being \(Wales\) Act 2014: expectations and experiences](#) research provided evidence from the service user and carer perspective to understand the impact the legislation had, the findings of which informed the 'From Act to Impact?' report. The study engaged with 101 carers. Participants raised concerns about the need for knowledge, understanding and awareness about the social service provisions under the SSWB Act, with some reporting challenges in accessing information and difficulties locating and understanding the information while managing their caring responsibilities. There was an expectation that it was the responsibility of professionals working with service users and carers to share, signpost, provide support to access and explain information and not to leave this for the service user or carer to locate by themselves. While some participants reported positive experiences of having their needs assessed, others expressed their frustrations that carers' needs assessments felt like 'tick-box' exercises. Other carers shared that they had not been able to gain an assessment, despite being eligible and wanting one. Others reported that they had found the assessment process disempowering and

unsupportive. Some participants reported their experience of assessments not translating into any practical support for them as carers and a lack of respite care. Some felt that there was a need to self-educate to ensure that their rights were upheld and their voice was heard. The research commented that carers often felt that they were unable to have their voice heard, listened to and acted upon and that great comfort would be taken from the knowledge and reassurance that, when they need to reach out, their voice would be heard and responded to, as the SSWB Act envisaged.

18. The conclusions of the '[From Act to Impact?](#)' report recognised that the context within which the SSWB Act was placed had altered over time and in unprecedented ways. The pandemic, workforce crisis and the cost of living crisis, combined with longer-term challenges around demography and austerity, had created new and acute realities which either did not exist at all in 2016, or at least not to the same extent. The study called for renewal and re-focus around the core principles of the SSWB Act.

19. In June 2023, Association of Directors of Social Services Cymru published its Welsh Government commissioned [Rapid review of how unpaid carers' rights have been upheld during and after the Covid-19 responses](#) report. The review was commissioned following the publication, in June 2022, of the Senedd's Health, Social Care and Sport Committee's [report](#) into hospital discharge and the impact on patient flow through hospitals. The Senedd's report recommended the Welsh Government should review whether carers' rights under the SSWB Act were being breached because of people having to take on more caring responsibilities than they may be willing or able to, due to lack of available services. The report's findings included that:

- There are waiting lists for carers' needs assessments in most areas, which prevents carers having the support they need.
- Many carers are not being offered assessments.
- There was a significant lack of awareness of carers' rights under the SSWB Act.
- Local authorities were proactive in trying to reach carers but recognised there was more to do.
- Identifying carers was not the responsibility of local authorities alone – GP surgeries and other health services should play a bigger role as part of a more integrated health and social care system.
- Feedback from carers indicated a deficit in meeting carers' needs, with respite care being the most significant unmet need.

- The contribution unpaid carers make to the social care system was undervalued and was not recognised sufficiently well for its role in preventing or delaying the need for statutory services.

20. In November 2023, Carers Wales published its [State of Caring 2023 report into the impact of caring on health](#) in Wales which summarised responses from 1,182 people who provide care and who completed an online survey between June and August 2023. It reported that many carers were feeling stressed, depressed and lonely. Further, it found that a significant proportion of carers were not seeking support with health conditions due to the demands of their caring role and many were unable to take a break from caring to do the things that might improve their wellbeing. Carers Wales said that some of the damage caused to carers' health and wellbeing as a result of their caring role was preventable with the right interventions, information advice and support. The report made several recommendations to the Welsh Government, NHS and local authorities. Its recommendations to local authorities were to increase resourcing to information and advice services so that more carers were aware of their rights under the SSWB Act and to work with national and local charities to create more health and wellbeing opportunities for carers in the community.

21. Carers Wales also published its [State of Caring 2023 report into the impact of caring on finances](#) in Wales report in November 2023. This report found that carers were struggling with their finances and that carers already struggling with the high cost of living were further impoverished by having their ability to earn restricted by Carers' Allowance. The report showed that carers worried about the impact of their caring role on their finances, for example, for fuel to attend hospital appointments, heating and specific dietary requirements. It also showed that many had cut back on seeing family and friends, an important life line for carers who often provided support and respite from sometimes long and lonely hours of caring.