

Track the Act: Review of findings 2016-2020

Unpaid carers' experiences of the Social Services and Well-being Act in 2016-20

Summary

This briefing summarises the key findings from the Track the Act evaluations conducted by Carers Wales between 2016 and 2020.

It shows that even before the Covid-19 pandemic it was evident that many of the legal rights carers have due to the Act were not being effectively translated into practice, raising questions about the consistency and effectiveness of the Act's implementation.

Introduction: Track the Act 2016-2020

Introduction to the Track the Act series

The Social Services and Well-being (Wales) Act 2014 created a legal duty on local authorities to assess the needs of unpaid carers, meet their eligible needs and promote their wellbeing. The Act came into force in April 2016. It was welcomed by unpaid carers and carer organisations for the wide-ranging new rights that it gave unpaid carers, and its potential to improve their lives. Upon the Act coming into force, Carers Wales commenced annual evaluations of the Act's impact on unpaid carers.

We gathered feedback from carers and local authorities, to consider whether practices have changed and what help and support carers can expect. Given the importance of health in identifying and supporting carers, we also sought feedback from local health boards.

It has not been our intention to provide a complete and detailed evaluation of the Act. Our responsibility is to give carers a voice, challenge shortfalls, highlight good practice and make recommendations on what improvements are needed to ensure that the Act is effective at making life better for carers.

The first “Track the Act” report was published in November 2016 and covered the first six months after the Act came into force. Subsequent reports were produced annually between 2016 and 2020.

- Track the Act 1 – First six months
- Track the Act 2 – First year
- Track the Act 3 – 2017-18
- Track the Act 4 – 2018-19
- Track the Act 5 – 2019-20

620 carers covering all 22 local authority areas responded to the survey for the 5th report, but the decision was taken to close the survey early in March 2020. This ensured the data would not be distorted by the beginning of the COVID-19 pandemic, nor impacted by the service changes imposed by the Health Protection (Coronavirus Restrictions) (Wales) Regulations 2020. This decision ensured data collected in 2019-2020 could still be effectively compared against data from previous years; enabling trends to be identified and conclusions drawn from several years’ worth of data.

The Social Services and Well-being Act (Wales) 2014 placed the following duties on local authorities

- Unpaid carers in Wales have equal legal rights for support as the people they look after.
- Local authorities should meet a carer’s eligible needs following a carer needs assessment.
- Local authorities must ensure that they have information, advice and assistance services in place and clearly signpost so carers can get the right information at the right time.
- Local authorities must promote the development of not-for-profit private organisations to provide care and support for carers as well as preventative services.
- Local authorities are required to promote the wellbeing of both people ‘in need’ and of their carers.

Carers are the vital third pillar of the health and care system in Wales. The future sustainability of their immense contribution, and the ability of local authorities and partners to uphold their legal rights and provide the support they need, requires full and effective implementation of the Social Services and Well-being Act.

Our surveys

Our surveys have asked carers about their experiences of Information, Advice and Assistance, Carers Needs Assessments and whether they receive any support with caring. 223 carers responded to our first survey, 517 to the second, 637 to the third, 532 to the fourth and 620 to the survey for Track the Act 5. In each of these

surveys we have had carers participate from all 22 local authority areas in Wales, providing a truly national picture.

We supplemented the data from carers by gathering information directly from local authorities and local health boards regarding their work with carers. We also analysed statistics published by the Welsh Government and the wider policy context relating to the rights of carers. This breadth of information has enabled us to formulate a well-rounded understanding of the implementation of the Act and the experiences of carers nationwide.

The questions used in our Track the Act surveys were revised slightly for each iteration based on carer feedback and in response to emerging issues. Because of this, some questions may have been asked for multiple years but not for the entirety of the Track the Act series 2016-2020.

The impact of Track the Act

Successive Track the Act reports have helped to raise awareness of the gap between the Act's provisions and the reality on the ground. Our reports have received national media coverage¹ and have given many carers the opportunity to directly share their story. We have been pleased to see some of our recommendations being adopted by the Welsh Government. Carers have consistently fed back to us that they value our work monitoring whether their rights are being realised in practice, and the series has additionally been valued by observers of the Act and stakeholders involved in delivering or analysing social care support in Wales.

Following repeated calls for a national Carers Rights Awareness campaign, the Welsh Government launched a public campaign to raise awareness of carers rights in Autumn 2019, with a revamped awareness campaign recently undertaken across October and November 2021². In 2019, the Senedd's Health and Social Care committee undertook an inquiry into the impact of the Social Services and Well-being Act on the lives of carers. We believe our growing evidence detailing shortcomings in implementation helped to convince the committee that an inquiry into the delivery of the Act was necessary.

National plans and evaluation

The report³ of the Senedd committee's inquiry was a comprehensive and broad evaluation of the Act, informed by evidence provided by a range of stakeholders. We welcomed the inquiry's findings and recommendations which echoed our own conclusions over successive Track the Act reports. Unfortunately, the Welsh Government's response⁴ to the committee's report was bland, lacking in specific

¹ ITV Wales (2018): Unpaid carers 'do not benefit' from law aimed to support them

² Welsh Government (2021): Promotional Material Carers' Rights

³ National Assembly for Wales (2019): Caring for our future An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers

⁴ Welsh Government (2020): Welsh Government response - 28 January 2020

commitments and a sense of urgency to address the widely-recognised problems with the implementation of their legislation.

Additionally, the Welsh Government funded the “Measuring the Mountain” project which ran from 2018 to 2020. The project used a variety of methods, including Citizens’ Juries, to examine the experiences of people accessing care and support in Wales. Like the Senedd inquiry before it, the conclusions of Measuring the Mountain were in tune with those from our Track the Act series.

In March 2021 the Welsh Government published its Strategy for Unpaid Carers⁵ with four national priorities to guide support for unpaid carers alongside the creation of a Carers Charter. Carers Wales, through our membership of the Ministerial Advisory Group on Carers, contributed towards development of this strategy and we were pleased to be involved in working groups to create the strategy’s delivery plan. The delivery plan⁶, published in November 2021, may improve some of the implementation failings associated with the Act, but there remains a pressing need for further action to correct persistent gaps in the Act’s implementation.

Information

Carers who see or are given information to help them care are more likely to achieve their desired personal outcomes and the wellbeing goals set out in the Act. Information about caring can also help individuals to identify themselves as a carer. Without adequate information, carers are more likely to feel alone and isolated; unsure where to turn to for support. Missing out on information, or receiving poor quality information, can have negative implications for a carers’ finances, their health as well as their ability to maintain employment alongside caring. Receiving good quality information, especially in the early stages of caring, may prevent carers from ultimately needing more substantial interventions.

Despite local authorities having a legal obligation since 2016 to provide Information, Advice and Assistance services and to proactively offer carers information on caring, successive Track the Act reports have found the proportion of carers seeing or receiving information is consistently low and on a downwards trend over several years. In 2016-17, Track the Act 2 found that 46% of carers had received information about caring. This recovered slightly to 53% in Track the Act 3 (2017-18), before falling to 45% in 2018-19 and falling still further in 2019-20 when only 38% of carers said in the Track the Act 5 survey that they had received information. This was a 15% decline on two years previously.

⁵ Welsh Government (2021): Strategy for Unpaid Carers

⁶ Welsh Government (2021): Strategy for Unpaid Carers: Delivery Plan 2021

Positively, an upwards trend can be observed regarding the proportion of carers who felt the information they received was useful. 78% of carers said the information they received in 2016-17 was useful, falling to 53% the following year but recovering strongly to 71% the year after and reaching 80% in 2019-20.

While most carers who receive information view it as useful, this varied based on the source of the information. Information from carers charities and disability charities has been consistently rated by carers as the most useful source of information, with 90% describing it as useful in Track the Act 3, 85% doing so in Track the Act 4 and 87% in Track the Act 5. The usefulness of information provided by local authorities varied from 72% to 76% over the same period. Concerningly, while 78% of carers said in 2017-18 that information provided by the NHS was useful, this declined sharply to 54% in 2018-19 and stayed at 54% in 2019-20, with only 52% of carers who had received information from GP surgeries rating it as useful in the same year, significantly below the mean weighted average of 80% for whether information from a source was useful in that year. More work is needed within local authorities and particularly within health settings to access and quality of information and we would suggest they consult with carers and relevant charities to co-produce and improve their information offering.

The 2019 Assembly inquiry into the Act⁷ called upon the Welsh Government to seek to standardise the Information, Advice and Assistance offer across local authorities to enable a consistent service and greater reach. Consideration needs to be given to the methods being used by local authorities to identify carers. Local authorities should further monitor how many carers have been identified across all their service provision and what information they have been provided with, including information on their right to a needs assessment. Local approaches to identifying carers and providing them with information should be monitored nationally.

Providing information to carers is rightly recognised as a priority in the new Strategy for Unpaid Carers. In Track the Act 5 we called for a *“large scale and coordinated awareness campaign to improve carer and carers’ rights awareness”*. We welcome the Welsh Government’s action on this and were pleased to be able to work with the Welsh Government and Carers Trust Wales on a revamped Carers Rights Awareness campaign which ran during October and November 2021.

Advice

Local authorities have an obligation under the Act to provide advice to carers. Advice can help carers to understand their rights, consider which services may meet their needs and arrange appropriate support for themselves or for the person they care for. To effectively advise carers, staff who interact with carers must

⁷ National Assembly for Wales (2019): Caring for our future An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers

understand the legal rights of carers, the challenges they can face and local service provision.

Despite the promise of the Act, our Track the Act series found that year after year only a minority of carers had received advice in the previous 12 months. In 2016-17 the proportion who had received advice in the previous year stood at 43%, reducing to 39% in 2017-18. 45% of carers said they had received advice in 2018-19, while 42% said they had the following year. The seemingly persistent failure to provide even a majority of carers with advice suggests the reality of this aspect of the Act is far from what was envisaged.

Encouragingly, a consistently high proportion of carers told us that they were asked about their caring role before being offered advice, with 78% and 82% of carers saying this happened in 2018-19 and 2019-20 respectively.

In a similar situation to that of information, most carers viewed the advice they received as useful (74% in Track the Act 5 and 72% in Track the Act 4), with the perceived usefulness of the advice similarly varying considerably by source. Advice from carers charities was consistently rated the most useful, with an average figure of 89% across the years 2017-18, 2018-19 and 2019-20. Advice from NHS sources was viewed as useful by 89% in 2017-18, though this had declined sharply to 66% by 2019-20. Advice from local authorities was generally rated the least useful, falling from 85% in 2016-17 to just 54% describing their advice as useful in 2019-20.

Throughout our Track the Act series we have consistently recommended that there should be mandatory carer awareness training for local authority, health board and social care staff who interact with carers. Training should include awareness of local support services and how those services could help carers in different situations. We feel this training would go a long way towards improving carer identification as well as the overall standard of advice provided. As a carers charity we are keen to support any organisation interested in reviewing their staff training or the advice and information they provide to carers.

19 of the 22 local authorities in Wales provided data⁸ to us on the number of carers they had provided information or advice to in 2019-20, totalling 35,098 occurrences. This was a welcome 31% increase on the previous years' figures when local authorities reported that 26,820 carers had received information or advice, but this still only equates to around 10% of the total carer population in Wales which stood at 370,000 in the 2011 census. This underlines the importance of the Welsh Government working with local authorities to ensure that a significantly larger proportion of carers can receive the information and advice they are entitled to under the Social Services and Well-being Act.

⁸ Carers Wales (2020): Track the Act 5

Carers Needs Assessments

The Act gives all carers a right to a Carers Needs Assessment. Local authorities must offer an assessment to any carer who it appears may have a need for support, regardless of their expected eligibility, and any carer can request an assessment. Carers have the right to ask to be re-assessed every twelve months, or whenever their caring situation changes.

Carers Needs Assessments are positioned as a central part of the Social Services and Well-being Act and are a gateway for carers to begin to receive support. Concerningly, it appears that a high and increasing proportion of carers have neither had, nor been offered, a carers needs assessment. In 2017-18 54% of carers in Track the Act 3 said they had not had an assessment in the previous 12 months, a figure which rose sharply to 85% in 2018-19 where it also remained for the following year.

More concerning still, our surveys over several years suggest the large majority of carers have not been offered an assessment at all since local authorities were given the legal obligation to offer them in 2016. In 2017-18, 73% of carers said they had neither had nor been offered an assessment since 2016. 69% said the same in 2018-19 and in 2019-20 over 7 in 10 carers (72%) said they had not had an assessment in any of the years since 2016. It appears that most carers are consistently missing out on a central plank of the 2014 Act. While it has been suggested that many carers refuse the offer of an assessment, our surveys do not bear this out. Across 2017-18, 2018-19 and 2019-20, on average only 8% of carers said they had declined to have an assessment after having been offered one.

In many local authorities the status of a 'what matters' conversation is ambiguous, with some using it in place of an assessment, whereas in other counties it is a precursor to an assessment. We would like to see consistent, clear language used to describe assessments, and for all core aspects of an assessment to be undertaken consistently. We will continue to work with Social Care Wales through our Carer Aware project to improve delivery of assessments by social workers.

Figures provided to us by 21 of the 22 local authorities in 2019-20 reported that 14,646 carers needs assessments or "what matters conversations" were delivered that year. Regrettably, this is a 22% decline in the number reported from the previous year and represents just 4% of the carer population in Wales. However, multiple local authorities highlighted that they were unable to distinguish whether a carer is being supported in their own right, or through a disabled person's needs assessment for the person they care for. While joint assessments may be preferred by some carers, they generally raise concerns as to whether the carers own wishes and rights are being discussed. Separate carers needs assessments should be offered to all carers. In those cases where their needs are assessed as part of a disabled person's needs assessment, the carer's needs should be recorded separately for clarity.

In successive Track the Act reports we have recommended the Welsh Government and local authorities take action to standardise the Carers Needs Assessment process across Wales to ensure a consistently higher standard that delivers on the intentions of the Act. Carers would benefit from standardised feedback following assessments, and information about appeals and how to complain if they are not satisfied with an aspect of the assessment.

Support and services

The Act places a duty upon local authorities to meet the eligible needs of a carer following an assessment. If a carer meets the eligibility criteria, they must be offered support and services to help them provide care and look after their own health and wellbeing. This could be in the form of direct payments to the carer, respite breaks, help with accessing education or a number of other interventions.

Despite this, our surveys have found a consistent majority of carers say they are caring alone without support, with 64% describing their situation this way in 2017-18, 57% in the following year and 62% in 2019-20. While not all carers will be eligible for support, data provided by 20 local authorities for Track the Act 5 showed that a very low proportion of the carer population appear to be receiving any support whatsoever, just 2,967 incidences equating to only 0.008% of the carer population based on the 2011 census. Among carers who had undergone a carers needs assessment there appears to be wide variability between counties regarding the proportion who are then given a support package, ranging from 62% in Carmarthenshire to just 4% in Caerphilly.

The significant variation in the provision of carers services and other forms of support across the country seriously undermines the implementation of the uniform legal rights to support which all carers in Wales have. In both Track the Act 4 and 5 we called upon the Welsh Government to “*ensure consistency in what support carers can access in each local authority area*” and to introduce a “*minimum service expectation based on eligibility criteria*”. The Senedd inquiry made a similar recommendation to tackle the evident postcode lottery in carer support, calling for a “*baseline range of support services based on eligibility criteria*”⁹. Regrettably, the Welsh Government’s response did not propose any new or bold solutions to achieve this. Carers need this to change.

Across Wales, many local authorities fund third sector organisations to deliver carers services. Short-term, precarious funding arrangements can reduce the effectiveness of these services as they find it difficult to plan for the future and social workers and other public services can struggle to signpost to an ever-

⁹ National Assembly for Wales (2019): Caring for our future An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers

changing menu of services that may cease to exist in the medium term. This turnover and instability makes it harder for carers to engage with services. Our Track the Act series and the Senedd inquiry both called for longer term, three-yearly funding settlements as a minimum from the Welsh Government. The Welsh Government has said it feels constrained by a lack of long-term funding commitments from the UK Government, but the Welsh Government should still consider how it can introduce more stability and sustainability into the funding system for carers services.

Other Principles of the Social Services and Well-being Act

In this report we have expanded our focus beyond the aspects of the Act evaluated through our survey questions to encompass other core principles of the Act which relate to carers. We have summarised the issues around each principle and posed questions for the Welsh Government and other decision makers on their application since 2016.

Social enterprises

The Act places a duty on local authorities to increase preventative services in the community to prevent the escalation of critical needs. To achieve this aim, Part 2 of section 16 of the Act requires local authorities to promote social enterprises, co-operatives, user-led services and the third sector to deliver care and support and preventative services. In doing this, the Act promotes a role for diverse providers of care and support services alongside the central role of local authority services.

The Act recognises that nurturing alternative providers may help to alleviate pressure on statutory social care services, but regrettably we have seen only limited engagement from local authorities and regional partnership boards over the years on this issue despite the duty in the Act. This situation poses a number of questions with regards to social enterprises and preventative initiatives.

- Have more social enterprises and co-operatives who provide services to carers been established since the Act came into force in 2016?
- What steps are local authorities taking to support carers to start their own social enterprises and similar?
- How is the Welsh Government monitoring the progress of local authorities in fulfilling this duty under the Act?

Advocacy

Advocacy services support people to express their views, wishes and feelings. They help people to secure their rights, have their voice heard and obtain the services

they need. The Act rightly highlights the importance of advocacy and says that professionals must identify from their first contact with an individual whether they require advocacy support.

Concerningly, Track the Act 5 found that 86% of carers were not offered advocacy before undertaking a Carers Needs Assessment, while 79% of carers said advocacy services were not discussed during their assessment in Track the Act 4. While not every carer will be assessed as requiring advocacy, a situation where the vast majority are not offered it suggests professionals have insufficient training to identify need for advocacy or are reluctant to discuss it. This impairs the ability of many carers to access services and support.

More positively, several local authorities have highlighted expanded advocacy provision in their areas. In Track the Act 5 we welcomed the launch of Gwent Advocacy service supporting Blaenau Gwent and Newport amongst other areas, the Eiriol advocacy program in Carmarthenshire and Denbighshire's in-house advocacy programme. Many advocacy services have a distinct focus on certain demographics eg. older people, people with learning disabilities, people with mental health problems etc. While targeted services bring valuable expertise, those commissioning services should ensure there are advocacy services available locally that anyone in need can access.

- Are all local authorities confident they have now commissioned sufficient advocacy services to meet local needs?
- How are local authorities measuring unmet need for advocacy?
- How is user satisfaction of existing advocacy provision being monitored?

Voice and Control

The Act states that statutory bodies and those undertaking assessments must consider whether a carer is “able and willing” to provide care. This means that all carers have a choice as to whether they care, how much care they wish to provide and on the aspects of care they are content to assist with. Accordingly, the Act says the carers needs assessments must consider the wishes of carers and give them a meaningful say in the design of care or support packages.

Patchy adherence to the Act's principle of voice and control risks masking the true level of need among carers and can force carers to maintain unsustainable levels of care leading to negative physical and psychological effects on both them and the person or people they care for.

- How are local authorities measuring unmet needs regarding carers to enable accurate service planning locally and also regionally through Population Needs Assessments?
- How are local authorities monitoring and reforming practice in the delivery of carers needs assessments to ensure the principle of voice and control is adequately addressed in every assessment?

Measuring performance

Through this process it became apparent that local authorities were recording and interpreting data in markedly different ways. While this presented challenges for this series of evaluations, it more importantly has impeded the ability of policy makers and officials at different levels to effectively measure the implementation of the Act.

For example, in 2018-19 the majority of local authorities were unable to distinguish in their records between carers needs assessments that had been offered to carers, and those that had been requested by carers, obscuring the extent to which an onus may be being placed on carers to ask for the assessments they should be offered. Some local authorities were categorising things like drop-in information surgeries at GP practices and distribution of carers emergency cards as support services, when arguably they should be categorised as information and advice. Similarly, some local authorities were unable to distinguish whether a carer was being supported through a disabled persons needs assessment, or through an assessment in their own right.

A lack of consistency in data collection was identified as an issue within the North Wales Population Needs Assessment mentioned in Track the Act 3, with the assessment remarking that data on the number of carers needs assessments was omitted as it gave a “*misleading picture as the numbers were counted differently in each county*”, with the Regional Partnership Board recommending a “*consistent approach to assessments and data recording*”. Following a recommendation from the 2019 Senedd inquiry that the Welsh Government should take a stronger lead on improving data collection on carer services, the Welsh Government indicated that this issue would be addressed both through the Strategy for Unpaid Carers and the Performance and Improvement Framework for data collection.

Improving implementation

The Social Services and Well-being Act represents a comprehensive framework for carer support. Unfortunately, it is abundantly clear that the Act’s implementation since 2016 has not lived up to the Act’s promise. The 2019 Welsh Assembly inquiry called upon the Welsh Government to “*take greater ownership*” of the Act’s delivery, echoing a call we have made throughout the Track the Act series. The inquiry further questioned whether there has been sufficient national funding to deliver the Act, a common complaint of practitioners which the Welsh Government should also address. While the Strategy for Unpaid Carers may help with clarifying expectations around the delivery of the Act, we believe the Welsh Government

needs to be more actively involved and transparent in monitoring implementation of the legislation.

Unpaid carers save Wales billions of pounds every year. If implementation issues are to persist, we would have serious concerns about the ability of hundreds of thousands of carers across Wales to continue caring. Ultimately, if carers are no longer able to care the state will have to step in, potentially placing huge additional burdens on the NHS and local government at a time when both are already stretched.

Recommendations for the Welsh Government, health boards and local authorities can be found in the Track the Act reports. Carers Wales remains committed to working with the Welsh Government, local government, partners in health and social care and carers across Wales to work on shared solutions. We want to see this legislation deliver for carers and would welcome approaches from any interested partners on how we can collaborate to make this happen.