

Track **the Act**

Briefing 4

Monitoring the 3rd year of
implementation of the Social
Services and Well-being
(Wales) Act 2014



Foreword

Across Wales there are 370,000 carers who, unpaid support a loved one who is older, disabled or seriously ill. Carers across Wales provide 96% of care and as our loved ones are living longer with illness or disability, more and more of us will be looking after them.

Legislation passed in Wales in 2014 was ground-breaking in creating a legal duty on local authorities to carry out needs assessments on carers and to meet their eligible needs.

This briefing from Carers Wales outlines the key findings and recommendations from our work in monitoring how effectively the Social Services and Well-being (Wales) 2014 Act (the Act) is being delivered, with a specific focus on unpaid carers.

It is the fourth annual briefing and covers the third year of the Act's implementation, from 6 April 2018 to 6 April 2019.

In light of the findings from our research we have highlighted recommendations that Carers Wales believe need to be undertaken to remove the barriers in place that are preventing the successful implementation of the Act for the benefit of carers.

Our evidence paints a disappointing picture that **implementation of the Act is failing to make a real impact on the lives of too many carers across Wales**. In the majority of cases equal rights do not exist for carers. This has inevitably led to carers feeling disillusioned and demoralised. **Many carers have told us that things have in fact worsened over the last few years**, as budgets have reduced across local authorities and local health boards in real terms. In addition to expectations of support being raised but not materialised following the passing of the Act. Further proof of the failings in the current system is highlighted in our evidence that carers who have received a needs assessment since the Act was passed have not returned for subsequent assessments, as the assessment did not result in any change in their circumstances.



I phoned the local authority asking for help for my son and was told that there was no help for him and I have to seek out my own support.

My health and well-being has deteriorated and I worry about what I will do if I have to give up my part-time job.



45%

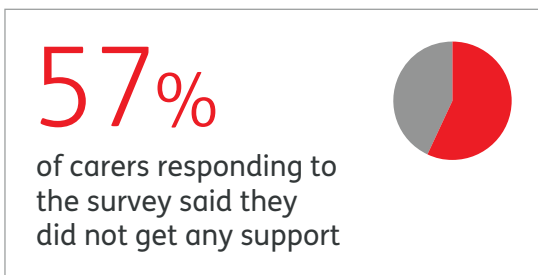


of carers responding to the survey said they have seen or been given information to help them care

Despite progress in some areas, such as the development of performance measures for local authorities, and the development of a national toolkit to help carry out needs assessment, our evidence shows that too many carers are still missing out on vital information, sources of local help and assistance. Over the last year only 45% of those who responded to the survey said they have seen or been given information to help them care. **This is a drop of 8% since last year.**

When we asked carers how they got an assessment, more than half asked for one themselves (56%), rather than being offered one. We are also concerned about what is being discussed during the assessments, as more than half of the respondents who did have an assessment weren't asked about their work situation and less than half (40%) had a discussion about emergency planning.

Many carers will not require substantial or statutory support but may have informal or third sector support in place to help them continue with their caring role. This support will often differ at different stages of their caring journey, **but 57% of carers responding to the survey said they did not get any support, indeed only 4% said they had their own support package from a carers assessment.**



Identifying and recognising carers is still a challenge, as many carers do not self-identify. As a result, local authority Information, Advice and Assistance services need to be effectively publicised and there needs to be proactive identification of carers through frontline staff.

The data we received from local authorities, as in previous briefings, reveals that the lack of a national framework for recording information means that the information provided differs greatly across Wales. We recognise that Welsh Government has developed a new performance measurement framework for local authorities, with a specific section relating to carers. This will be implemented from April 2020 which is a positive step.

There is strong evidence that the process of offering assessments is now being established amongst local authorities. However the data also illustrates the large discrepancies in assessments being offered by different local authorities.

There is also a significant question over how many carers are aware that they have been offered or have been given an assessment.

Given the disappointing impact of the legislation to date and the lack of action following our research recommendations last year, we are now calling on **national action from Welsh Government.** We believe it is time to be honest about the reality that is facing too many carers across Wales, especially as we know Welsh Government policy will result in a substantial increase in the number of carers across Wales over the years ahead. Welsh Government should acknowledge that its policy, such as 'A Healthier Wales' will impact directly on unpaid carers as care moves from formal health settings to the home.

Given the evidence presented about the problems with the implementation of the Act, we urgently call on the Welsh Government to demonstrate strategic leadership in developing it's Action Plan for Carers. The plan should clarify expectations, progress culture change and get rid of the many barriers in place preventing the implementation Act.

With the expectation that social services and health budgets are unlikely to rise substantially in real terms over the years ahead, the role of unpaid carers will therefore be of even more significance. This plan needs to ensure the correct structures are in place now to support carers and that there is capacity to deal with the anticipated increase in the number of unpaid carers across Wales.

Carers Wales would like to thank those carers and all local authorities and health boards that engaged with us to produce the evidence presented in this briefing. We are extremely pleased with the level of engagement which has enabled us to present a comprehensive picture.

We strongly believe that all stakeholders share our genuine desire to ensure the successful implementation of the Act for the benefit of unpaid carers across Wales. It is clear that capacity and the systems in place at the moment are hindering this ground breaking legislation from being realised. With this in mind we hope the recommendations are received and accepted in the way that they are intended.

Carers Wales wants a society that respects, values and supports carers, and our mission is to make life better for carers.

Carers save the Welsh economy £8.1 billion a year. The number of carers will increase in the years to come as people live longer, with more life limiting disabilities. It would be a false economy not to invest and plan services to meet carers needs and support them to look after their own health and well-being.

Claire Morgan
Director
Carers Wales



Recommendations

Welsh Government

Recommendation:

Given the evidence presented about the problems with the implementation of the Act, we urgently call on the Welsh Government to demonstrate strategic leadership in developing it's Action Plan for Carers. The plan should:

- clarify expectations, progress culture change and embed process to ensure the legislation is implemented by Welsh Government, local authorities and local health boards
- prepare for the increasing role of carers over the next 10 years
- establish a maximum wait time for carers to receive their needs assessment
- ensure consistency in what support carers can access in each local authority across Wales to include a minimum service expectation based on eligibility criteria
- standardise feedback carers receive following their carers needs assessment
- standardise a carers needs assessment appeals process
- direct local health boards to identify, provide information and support for carers
- review the role and effectiveness of the Ministerial Advisory Group on Carers (MAG) and its ability to oversee the plan

Recommendation: Welsh Government funding cycles should be on a longer term basis of three years in order to help enable improved planning and sustainability of services for carers.

Recommendation: Welsh Government to share information about how it's funding has been used for the benefit of carers.

Recommendation: Welsh Government should fund and deliver a large scale, co-ordinated awareness campaign to improve awareness of carers across society, as many carers turn to family and friends for support.

Recommendation: Relevant Welsh Government teams should work with Carers Wales 'Employers for Carers Hub' to ensure improvements in the ways carers are supported at work and ensure working carers do not miss out on information advice and assistance.

Local authority

Recommendation: Local authorities to encourage staff to utilise tools such as the Social Care Wales Carers Needs Assessment best practice toolkit to improve delivery of Carers Needs Assessments.

Recommendation: Local authorities should prepare effectively for the introduction of the new performance measures and data capture guidelines that will be implemented from April 2020 so that meaningful and comparable information can be collected.

Recommendation: Local authorities to carefully consider how they are targeting and promoting their Information, Advice and Assistance (IAA) services to reach a wider cross section of carers.

Partnerships

Recommendation: There should be improvements in multi-agency working by local authorities, local health boards and third sector providers to better co-ordinate what is offered to carers.

Recommendation: Local authorities and local health boards to better consider how carers can be supported in an emergency, both in terms of emergency planning through the Carers Needs Assessment and in the event of an emergency.

Recommendation: Local authorities and local health boards to consider how they support carers across their departments, repurpose funding and plans to address the needs of carers.



Contents

	page
1. Background	6
2. Our research approach	7
3. Carers survey results	8
3.1 Information	9
3.2 Advice	11
3.3 Carers needs assessments	12
3.4 Support	14
4. Local authority evidence	16
4.1 Providing Information, Advice and Assistance and Needs Assessments	17
4.2 Good Practice	22
4.3 Future plans to support carers	22
4.4 Barriers and obstacles	23
5. Local health board evidence	24
5.1 Use of funding	25
5.2 Future plans and barriers to supporting carers	26
6. Policy context	27

1. Background

It has been a priority of Carers Wales to review the Social Services and Well-being (Wales) Act's (the Act) implementation and delivery as it relates to carers. To do this we have 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 have also sought feedback from local health boards.

It is not 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 Act should now be fully embedded and places 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 signposting 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 and support for carers and preventative services
- Local authorities are required to promote the well-being of both people 'in need' and of their carers

There have been three previous Track the Act briefings covering the first two years of the Act (available on the Carers Wales website). These identified key recommendations for local authorities and Welsh Government to ensure the successful implementation of the Act.

Last year we made a recommendation to Welsh Government, via the Ministerial Advisory Group on Carers to honestly identify and assess the obstacles and barriers frustrating the successful roll out of the legislation. Given the hiatus of this Group, this has not happened in any detail. However, we are pleased that other recommendations have been actioned, such as a national carers awareness programme scheduled for this autumn and the development of new social services performance and improvement data collection metrics for local authorities, which now includes a section on unpaid carers (to be implemented from April 2020). We also welcome the continued funding to the Regional Partnership Boards, which includes a funding requirement to support carers and the development of the Social Care Wales toolkit on Carers Needs Assessments (assessments).



2. Our research approach

To understand how the Act is being implemented we have used several different research methodologies.

We have:

- Collated direct feedback from carers through our Track the Act survey, asking about their experiences of Advice, Information and Assistance, Carers Needs Assessments and whether or not they received any support
- Sought and received information directly from local authorities and local health boards, regarding their work with carers
- Analysed statistics published by the Welsh Government
- Analysed how wider policy context affects the rights of carers

We have presented the research findings as follows:

- Track the Act Carers Survey results
- Feedback received from local authorities
- Feedback received from local health boards



3. Carers survey results

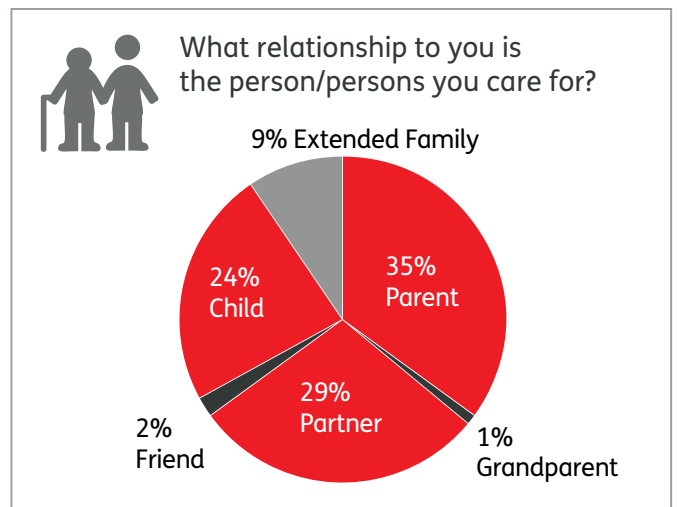
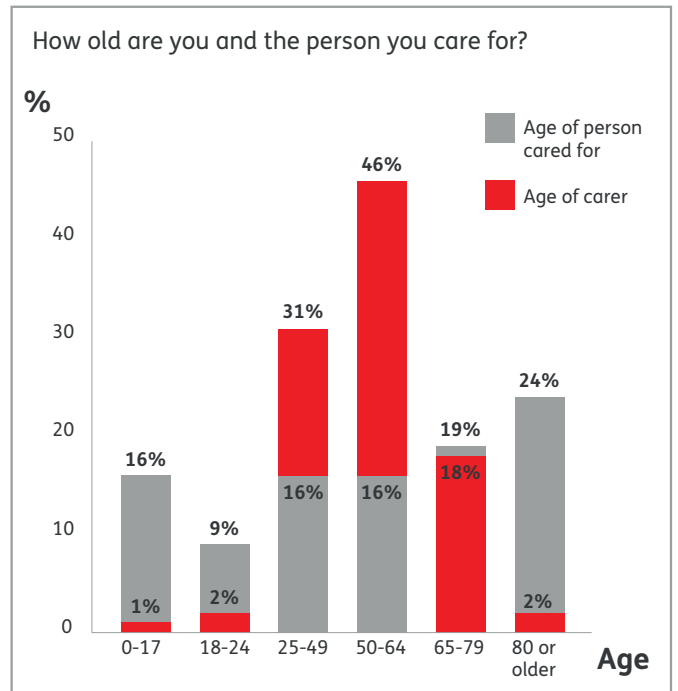
This year we had a good response with 562 carers completing the survey. This represents people from all of 22 local authority areas. 7 respondents were from local authorities outside of Wales, however they had their assessments undertaken by the authority where the person they care for resides. We would like to thank all the carers who responded and shared their lived experience of the Act’s implementation.

The information we gathered indicates that they are caring for a significant number of hours (74% caring for over 35 hours per week) and the majority (79%) being of working age.

Our statistics highlight that those who require care can be of any age but the ageing population means that there is an increasing need for older people to be cared for. 41% of respondents told us that they are caring for someone aged between 0-49 and 59% caring for someone aged 50 and over.

The majority of the respondents are at the more intensive end of caring, with 61% caring over 50 hours a week and 44% caring over 90 hours.

Only 5% said they had been caring for under a year while 69% said that they had been caring for over five or more years. The largest proportion of respondents (88%) indicated that they were primarily caring for a parent, partner or child.



How many hours do you care for someone	
	2018-19
0 to 9 hours a week	7%
10 to 19 hours a week	9%
20 to 34 hours a week	10%
35 to 49 hours a week	13%
50 to 69 hours a week	8%
70 to 89 hours	9%
90 hours or more	44%

Survey question feedback

The Act placed a statutory legal duty on local authorities to identify carers and provide them with Information, Advice and Assistance relating to care and support. Local authorities must also offer carers assistance in accessing that care and support. Our survey asked carers about their experiences of Advice, Information and Assistance, Carers Needs Assessments and whether or not they received any support.

3.1 Information

Accessing relevant information can have a significant impact on carers' lives. Those who see or are given information are more likely to achieve positive well-being goals and personal outcomes as defined in the Act. Carers are less likely to need a more formal assessment, if they have been able to access help and informal support earlier in the caring journey.

Those who miss out on information could face difficulties such as financial hardship, developing poor physical and mental health, struggling or being unable to maintain all or some aspects of their caring role and have difficulty balancing work with caring.

Our evidence shows that too many carers are still missing out on vital information, sources of local help and assistance and how to access it. Over the last year only 45% of those who responded to the survey said they have seen or been given information to help them care. This is a drop of 8% since Track the Act 3. This raises questions about how information is being promoted. From further analysis of the data, accessing information is impacted by the age of the carer. Respondents between the ages of 25 to 49 are the least likely to have seen information (35%) compared with those aged 50+ (50%). This suggests that many working carers could be missing out on information. This is concerning given almost two thirds of the carer population in Wales (223,000) are working carers (Carers UK, 2019).



I am lucky to have run into a person doing information at an event who gave me leaflets on being a carer



I asked a specific question and got the information required



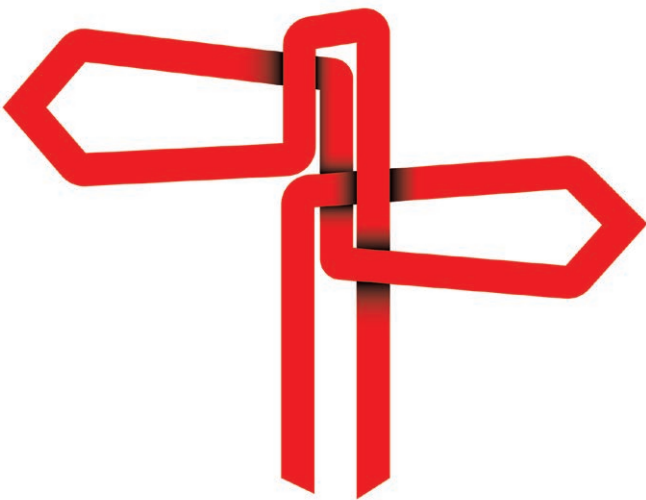
If you do not ask, you do not get the help you need



I am satisfied with all the help and information I have received over the past 12 months



Track the Act respondents 2018-2019

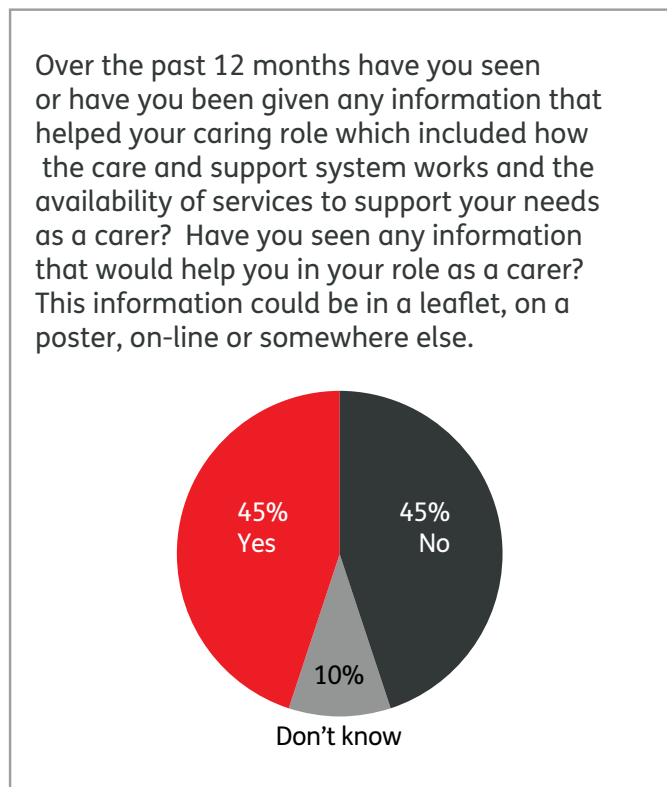


Our evidence also shows that carers who report seeing information go on to seek further information from other sources. The survey indicated that on average carers sought information from two or three other sources after receiving the initial information.

We asked those who had received information if they found the information provided helpful or useful. On average 71% of carers found the information useful but there were distinct differences in the satisfaction levels depending on who provided the information.

Carer charities and disability charities were considered the best for providing information with an 85% satisfaction rating. 75% of respondents said that local authority information was useful or helpful. However those accessing information through the NHS were less satisfied with the information provided, with only 54% saying that it was useful or helpful. This highlights the importance of third sector organisations in delivering the Act.

Identifying and recognising carers is still a challenge, as many carers do not self-identify. As a result, local authority Information, Advice and Assistance services need to be effectively publicised and there needs to be proactive identification of carers through frontline staff.



If I had not pursued every avenue to inform myself via charities of my legal rights and what should happen prior to trying to negotiate our needs with the council, as they don't help at all



How would I know about the help? Where is it advertised?



I am still finding my way around the support system



I feel as though all you are offered is a phone number, email address or leaflet. I want practical help



There is a distinct lack of information for carers about what is available for them and even then, it can be a fight to get help



Track the Act respondents 2018-2019

3.2 Advice

Advice is when organisations work co-productively with a carer to explore their situation and the options available to them to meet their personal and well-being outcomes. It is imperative that carers understand what is available to them and that they are actively involved in making decisions about what matters to them and the personal outcomes they wish to achieve. Advice is generally provided face to face or over the telephone.

The number of carers who have received advice has increased by 6% from Track the Act 3 (39%). Our data shows a strong correlation between those having received information and those accessing advice.

On average 74% of carers found the advice, from whatever source, helpful or useful. However there were distinct differences in how satisfied carers were depending on the source giving the advice. Carer charities and disability charities were considered the best with 87% saying they found the advice that they needed. The satisfaction level with others varied. 80% of those who received advice said that they would go back for more.

81% said that the advice they received helped them to continue caring, 67% said it improved their caring role and 58% said it supported them to have a life alongside caring.

From this we can conclude that there is a distinct desire from carers to gather advice to help them with their caring role, when they know that such support is available. It also reinforces how important receiving timely and appropriate advice is to enabling carers to remain resilient and preventing them from requiring more formal support. Once carers seek the information and advice available, they are more able to help meet their own needs.

The results also showed that parent carers were less likely to have received advice than those looking after a parent or partner and that 22% of respondents receiving advice were not asked about their personal circumstances before being given advice.



“ Got in touch with PAVO community connector who came to see me ”

“ We get no help, no advice and no support ”

“ I would recommend to anyone to always seek guidance and support before caring for someone else, a carer should make sure they are also able to care for themselves ”

Track the Act respondents 2018-2019



3.3 Carers needs assessments

A carer's needs assessment is a legal entitlement for all carers. Where it appears to a local authority that a carer may have needs for support, they must assess whether the carer has needs for support (or are likely to do so in the future) and what those needs are.

85% of carers who responded to this year's Track the Act survey said that they had not had an assessment in the last twelve months, with 7 in 10 saying they hadn't had an assessment since the Act's implementation. Given that 61% of carers who responded to the survey said they were caring for over 50 hours a week and 69% said they had been caring for over five years, we find this figure worrying.



Interestingly, only 17% of carers stated that they did not want an assessment, with 15% saying they did not have the time or energy to have an assessment.

When we asked carers how they got an assessment, more than half asked for one themselves (56%), rather than being offered one.

From the survey respondents who did have an assessment (63 carers), we have concerns about what is being covered within the assessments. For example, only 67% were asked about what parts of caring the carer was willing and able to do. More than half weren't asked about their work situation and less than half (40%) had a discussion about emergency planning. Planning for emergencies is a priority for carers. Carers want peace of mind that in the event that should something happen to them, the person they look after will have an immediate response to any help and assistance they need.



Still waiting for someone to contact me. Two months now



I did not know what a carer's assessment was. I have been to many medical appointments with my parent and it was never mentioned. I don't think enough is done to make it easy to get help



Sometimes I am very low as I worry about my mum especially if I have to go into hospital, as it's always an emergency admission



Emergency support from the council needs 5 days notification!



When I asked about emergency care, I was told that social services is not a babysitting service



Track the Act respondents 2018-2019

Furthermore, the majority were not offered any advocacy support and 22% said they did not receive any feedback following an assessment or ‘what matters’ conversation i.e. whether or not they were deemed to have any eligible needs. Only 44% were given a copy of their assessment. Without feedback or a copy of the assessment, carers are unable to challenge decisions through the local authority complaints procedure. There is no appeal process within the regulations or the Act to expedite matters. Complaints take time and effort, so many carers tell us they do not progress with a complaint despite feeling aggrieved.

Three years after the commencement of the Act, we remain concerned that those with the most intensive caring responsibilities seem to not be accessing or receiving assessments and the potential support they may be entitled to. For those who do have an assessment we are concerned about the gaps in what the assessments are covering.



I am aware I can ask for an assessment but haven't requested one



The person who assessed me in April 2018 said she had never done a carer's assessment before. She had never had a carer ask for help for herself before. She told me that they assess the child and then decide if there are any barriers to the parent being able to meet the child's assessed needs



The re-assessment process is disgusting and the months you are left without answers is a huge cause of stress and upset because your life is being left in a limbo. There needs to be a timescale on these things



of people who have not had a Carers Needs Assessment have not been offered one or did not want one



I had to wait 6 months for a carers assessment. Still waiting for help with my mother's personal care. She is 98. I am 70



There is little point in a carers assessment as there is nothing available that doesn't have to be paid for



I had a carers assessment years ago. I didn't benefit in any way. I can't see the point



I don't really understand the carers assessment and don't see how it can help me, so just carry on as best I can



I have been a carer for over 30 years and am extremely worn out. I cannot face the complaints process



Track the Act respondents 2018-2019

3.4 Support

Carers are not a homogeneous group of people. All will have varying caring responsibilities and different needs, at different times, dependent on their own personal circumstances. Many carers will not require substantial or statutory support but may have informal or third sector support in place to help them continue with their caring role. This support will often differ at different stages of their caring journey.

- 57% of carers responding to the survey said they did not get any support
- 36% said they rely on family and friends
- 27% of those who did receive support also cited family and friends as a critical source of support
- 25% said they get help as part of the care package for the person they care for

Only 4% said they had their own support package from an assessment. Some may be getting indirect support through the children’s and disabled person’s care plan, however given that carers have been afforded equal rights to support, it is disappointing that this is such a low figure.

Family and friends providing support to carers would be classed as carers themselves under the Act. This suggests that there are a cohort of people within the care circle around a cared-for person who may also be unaware of their rights and support available.



Why offer something that they can't deliver



The Act is all very well in theory but in the present financial climate that's all it is



We also continue to remain concerned that carers are being signposted to community services or, are paying privately for help. If for example, carers are paying for a range of services themselves in the community, the cumulative impact on charges may mean the difference between the carer taking up services to meet their needs or struggling on. Alternatively where carers chose to pay, this can have a detrimental impact on their personal finances. In either case, this will inevitably have consequences on their own health, personal and well-being outcomes and crucially their ability to continue to care.

For those who answered that they get support, help or assistance, we asked where did it come from	
Friends and family	27%
Council package from care plan for the person I care for	25%
Paid cleaner or other service company	12%
Free charity assistance	9%
Paid local council service	6%
Paid private agency/business	6%
Council care package from carers needs assessment	4%
NHS Continued Healthcare support package	4%
Other	4%
Paid charity assistance	1%



The assistance offered by social services revolves around fitting people into what they have available, rather than the bespoke needs of the individual



I was offered a spa day, what I actually needed was a support package for my son





4. Local authority evidence

To gather information and monitor how the Act is being implemented across Wales, we have requested information from all local authorities in Wales as the Act's implementation is primarily their responsibility.

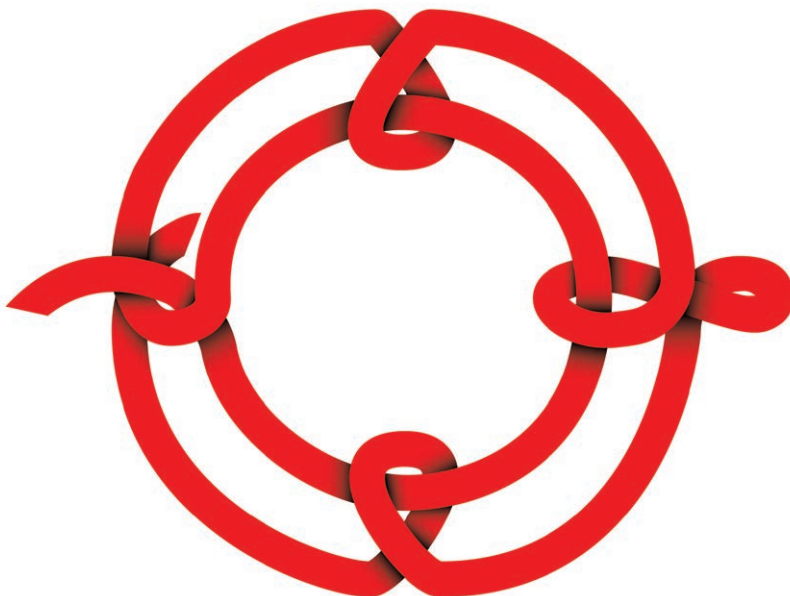
For the first time, Carers Wales received information from all 22 local authorities for 2018/19. We have summarised the data received in this briefing. The full responses are published on our website. We would like to thank all the authorities for their responses.

The responses returned were not in a standardised format and this has resulted in answers being significantly varied.

Carers Wales has reported all information received as it was presented by the respondent. Discrepancies in the data between responses have been highlighted in the narrative where relevant.

The data we received from local authorities, as in previous briefings, reveals that the lack of a national framework for recording IAA means that the information provided differs greatly across Wales. We recognise that Welsh Government have developed a new performance measurement framework for local authorities, with a specific section relating to carers. This will be implemented from April 2020 which is a positive step.

To represent these figures in a comparable format, Carers Wales has combined all received numbers into a total figure. We did this under the interpretation of each local authority's answers. This means that there are some large discrepancies within the data due to varied interpretation of the individual questions which is discussed within the narrative of each segment.



4.1 Providing information, advice and assistance and needs assessments

We asked each local authority how many carers:

- Were provided with information, advice and assistance (IAA)?
- Were offered a Carers Needs Assessment (CNA) / What Matters Conversation?
- Received a support package or direct payments to meet their needs in their own right?

County	Carer Population	IAA	CNA	Support
Anglesey	8042	41	563	409
Blaenau Gwent	8752	2220	542	0
Bridgend	17919	2104	1511	19
Caerphilly	22721	NIR	NIR	NIR
Cardiff	35005	908	3139	3
Carmarthenshire	23989	315	1256	540
Ceredigion	8603	977	895	176
Conwy	13605	NIR	867	483
Denbighshire	11631	410	533	199
Flintshire	17643	8996	2055	4164
Gwynedd	12443	129	42	10
Merthyr Tydfil	7427	3	223	114
Monmouthshire	11491	1593	1146	99
Neath Port Talbot	20365	608	437	NIR
Newport	16604	1033	71	22
Pembrokeshire	15195	3009	580	185
Powys	16154	3172	621	55
Rhondda Cynon Taff	29640	NIR	891	84
Swansea	30349	NIR	2166	30788
Torfaen	15575	133	420	NIR
Vale of Glamorgan	11929	259	403	316
Wrexham	15148	910	353	59
Total	370230	26820	18714	37725

Key: No Information Returned (NIR)

Information, advice and assistance

18 of the 22 local authorities in Wales were able to give figures for how many carers were provided with information, advice and assistance (IAA) totalling 26,820.

Of the 4 local authorities that could not provide figures, Caerphilly, Conwy and Swansea reported that they do not keep this data on file and Rhondda Cynon Taff did not answer the question.

The number of instances of IAA varies widely from a high of 8996 reported by Flintshire and a low of 3 reported by Merthyr Tydfil. **This makes the data difficult to analyse with any certainty.**

The large discrepancies between these reported numbers could be partly explained by how the data is collected. For example, from those local authorities who have broken down their data, Blaenau Gwent revealed that 2115 of their instances were through their Carers Engagement team with another 105 via their IAA team, while Wrexham reported the number of instances via their contracted work through NEWCIS (915) but did not have any internal records of carers directly contacting them. As a result, the response is unlikely to provide a complete picture of carers receiving IAA. This is illustrated further by Neath Port Talbot who reported 608 instances of direct contact but evidenced another 3871 contacts (via the question 'how many carers were supported in another way') highlighting the provision of IAA through other services.

This highlights improvements needed in data collection, so local authorities have an accurate picture of how many carers they are supporting.

Carers Needs Assessment / What Matters Conversation

21 of the 22 local authorities were able to report how many carers were offered Assessments/ What Matters Conversations totalling 18,714. Only Caerphilly was not able to return this information.

This reported number is a 203% increase on the official Welsh Government figures for 2017/18 (6,178)ⁱⁱ. The official figures for 2018/19 were not available at the time of writing this report.

This is strong evidence that the process of offering assessments is now being established amongst local authorities. However this also illustrates the large discrepancies of assessments being offered by different local authorities.

It should be noted that figures cannot be compared accurately as population density is a factor in the number of assessments that could be potentially undertaken. To aid comparison, we have included carer population numbers from the 2011 Census.

The lack of a consistent framework for collecting data is also a factor when comparing these figures.

There is also a significant question over how many carers are aware that they have been offered or have been given an assessment. Information from the carers survey responses and additional commentary from Carers Wales outreach work strongly suggests that joint Children's/Disabled Needs Assessments and Carers Needs Assessments are being practiced without carers being informed of their rights. It should be stated that there can be advantages to undertaking a joint needs assessment and the system should allow for both these and separate Children's/Disabled Needs and Carers Needs Assessments. However it is the right of the carer to have this explained to them before any assessment is performed and they should be given the option to choose which type of assessment is most appropriate for their situation.

Additional information supplied by Ceredigion, Denbighshire, Rhondda Cynon Taff and Swansea show a high proportion of assessments rejected by carers. In total, this limited statistical group had 76% of the assessment offers rejected. This is a much higher figure than the 17% of carers who completed the Track The Act survey who said they did not want an assessment.

Due to the lack of information around how these assessments were offered, it is difficult to know why such high proportions were rejected. However evidence from our survey suggests that there is a general confusion in the process and a lack of confidence that there will be a positive effect for undergoing the process. This mistrust of the process is concerning.

This strongly suggests that a collaborative effort is needed between the Welsh Government, local authorities and third sector partners to understand why carers are choosing not to have an assessment and to improve the messaging of what an assessment is for to encourage carers to access this when it is required. We also believe that this, combined with information gleaned from the assessments, would help local authorities in planning carers services in future.

Support packages and direct payments

19 of the 22 local authorities were able to report how many carers received support packages or direct payments to meet their needs in their own right.

Three local authorities, Caerphilly, Neath Port Talbot and Torfaen were not able to report this information. Both Caerphilly and Torfaen stated this information was included with people receiving disabled needs support. Blaenau Gwent reported that 0 adult carer support packages are in place but there are combined packages that include support for the carer.

Direct comparisons of these figures cannot be achieved due to the differences in responses.

Swansea’s response of 30,788 cannot be attributed to direct support packages or direct payments to carers as the information they submitted relates to a list of all respite spaces in that local authority area. Consequently, this distorts the statistics.

There are also reporting differences on how small grants are recorded. Some local authorities have included this as direct support framework while others have included this with other ways carers were supported.

It is disappointing to see that 9 of the 19 local authorities (47%) who have reported on this question are offering less than 100 support packages in a carer’s own right. This lack of direct support may be a considerable reason why confidence amongst carers in the assessments may be diminishing and why so many assessments have been rejected in the sample size from the previous section.

However it is also important to note that the ethos of the Act was to support carer’s own personal goals and well-being. For many carers, these are unique to their situation and separate from those they care for. We expect individual carer support packages to become more prevalent, as the implementation of the Act increases awareness of what carers are entitled to.

How many carers were given an annual review of their existing carers needs assessment/support package?	
County	Figure
Anglesey	477
Blaenau Gwent	0
Bridgend	NIR
Caerphilly	NIR
Cardiff	91
Carmarthenshire	27
Ceredigion	29
Conwy	138
Denbighshire	NIR
Flintshire	989
Gwynedd	17
Merthyr Tydfil	74
Monmouthshire	34
Neath Port Talbot	8
Newport	22
Pembrokeshire	NIR
Powys	NIR
Rhondda Cynon Taff	NIR
Swansea	NIR
Torfaen	22
Vale Of Glamorgan	0
Wrexham	NIR
Total	1928

14 of the 22 local authorities were able to report how many carers were given an annual review of an existing assessment or support package.

It is unclear how many other local authorities who did provide figures were only submitting figures for support packages being reassessed and not assessments. Only Ceredigion provided information for both elements of the question and Conwy noted that Hafal were doing reassessments but they did not know how many has been completed. Merthyr Tydfil has put in a six month review process for young carers but there was no comment on what processes are available for adult carers.

Caerphilly stated that they do not review assessments but are open to any carer contacting them when their needs change and Torfaen included the caveat that the information they provided was for the cared for person only.

The process of re-evaluating also appears to have technical issues with several different local authorities stating that they did not keep this information, could not distinguish re-evaluations from new assessments or did not separate this information from disabled needs assessments.

Under the Act, it is the right of every carer to have their caring needs reassessed if their caring situation changes or every 12 months. From the responses received, it seems the onus is being put on the carer to seek a reassessment. This is particularly concerning as we believe many carers are not aware they are entitled to this right, may not understand at what point they should seek a reassessment based on a change in their caring responsibilities and may be sceptical about reassessment at 12 months given the delay many have experienced in receiving a previous assessment.

There are some positive practices such as Monmouthshire who are reminding carers of this process in their newsletters to carers.

We believe that reassessments are also challenging given that many carers do not receive any feedback following an assessment, unless they receive some assistance. We believe that carers should have a record of the assessment and the reasoning why support was, or was not, put in place. This becomes vitally important in the reassessment process as it is the evidence of how a caring journey has changed.

How many carers requested an assessment or a review of an existing assessment?

Only 8 of the 22 local authorities could report how many carers had requested an assessment, their responses ranging from 0 to 511. The majority commented that their systems did not distinguish between requested assessments and offered ones or did not have the capacity to record this information.

How many carers were supported in another way?	
County	Figure
Anglesey	NIR
Blaenau Gwent	2434
Bridgend	2798
Caerphilly	4710
Cardiff	NIR
Carmarthenshire	1233
Ceredigion	659
Conwy	493
Denbighshire	NIR
Flintshire	NIR
Gwynedd	NIR
Merthyr Tydfil	NIR
Monmouthshire	491
Neath Port Talbot	3871
Newport	116
Pembrokeshire	98
Powys	NIR
Rhondda Cynon Taff	NIR
Swansea	NIR
Torfaen	NIR
Vale Of Glamorgan	1199
Wrexham	910
Total	19012

Although only 12 of the 22 local authorities returned actual figures, all 22 local authorities gave named examples of other ways they were supporting carers. We are encouraged to see the variety of different programs being put in place to support carers.

There are differences in how the local authorities have chosen to provide for carers. Some are delivering support in house and others are outsourcing to third organisations. There is no statistical evidence that suggests any notable advantage or disadvantage to any of these approaches. However it does present an opportunity for local authorities to share successes and good practices to further develop ways to support carers.

Further deviations can be seen between local authorities in what elements they consider further support rather than IAA, although it should be noted that all local authorities referenced multiple strategies to support carers.

Blaenau Gwent highlighted 146 drop-in sessions supporting 2157 carers at GP surgeries. It is pleasing to see the innovation of reaching out to carers in a place that they are likely to visit. However it is an interesting discussion whether this should be considered additional support or a direct IAA service. Similarly Carmarthenshire described their carers emergency card as further support which could be considered as assistance to carers in their caring role.

There was a notable increase carers events from Track The Act 3. Newport noted activities including a spa day, art activities and a pamper day. While Pembrokeshire has supported various community-run groups assisted by small grants and the Vale of Glamorgan ran an introduction to complementary therapy session.

Whilst this variation of activity is positive and likely to increase inclusion, we are frequently contacted by carers in desperate need of immediate support. However they are told that the local authority does not have the funds available. At a time when budgets are so limited, we query the use of funds on well-being activities when some carers in desperate need of practical help.

There is great variation in whether local authorities directly deliver Information, Advice and Assistance services, undertake carers needs assessments and provide services themselves or through another provider.

Information and advice:

- 3 deliver themselves
- 18 deliver jointly between themselves and another provider
- 1 local authority did not answer

Carers Needs Assessments:

- 4 deliver themselves
- 16 deliver jointly between themselves and another provider
- 1 contracts out
- 1 local authority did not answer

The Act places a duty on local authorities to provide assessments that are proportionate to need. Many local authorities have taken a ‘What matters’ approach in having the initial conversation with carers. There is ambiguity across all local authorities in how an assessment is undertaken with some sending out forms for the carers to complete, others doing in-house assessments, others commissioning external services. Our concern continues to be that carers are unclear if their needs have been assessed.

We also asked local authorities how long did carers have to wait for an assessment after they requested one.

- 10 told us that they do not hold the information
- 5 said that they do Carers Needs Assessments within two weeks
- The remaining 7 local authorities ranged from 15 days to 18 weeks

It is clear from the carers survey responses that many carers are waiting months for an assessment. Our view is that local authorities should agree a maximum wait time, so that carers in desperate need are not left waiting for considerable periods of time. The ethos of the Act is prevention, however many carers are reaching crisis point as a result of not receiving timely support.

4.2 Good practice

We are encouraged by the wide-ranging and innovative practices that the local authority responses revealed. A range of approaches are being used at a local level to reach out to and provide information to carers, for example:

- Community connectors based in some local authority areas including Newport that support carers with information, advice and assistance and provide outreach community services.
- Carer outreach projects based in hospitals and GP surgeries eg. Carers Engagement GP scheme in Blaenau Gwent has enabled all the GPs surgeries to offer carers support, advice and signposting to relevant organisations and services.
- Investment in carer services through ICF funding. Examples include funding Carer Outreach Services in hospitals in Anglesey, Third Sector Integration Facilitators in Ceredigion whose role is to work across sectors to raise awareness of third sector services that support carers and in Powys co-production of a respite project to plan bespoke respite opportunities for carers.
- Commissioned services through third sector and carer organisations eg. Neath Port Talbot council have commissioned Neath Port Talbot Carers Service to provide Information, Advice and Assistance and undertake assessments.

- Internal carer support workers within the local authority eg. Conwy has an in-house carers support team that comprises of a manager and three full time carers officers linked to Community Resource Teams across the local authority area.

Many of these are in the early phases of their development so the impact is unlikely to be fully realised within project timeframes and will be difficult to measure positive outcomes for carers. Funding is an issue however, with many projects working to annual funding streams.

As mentioned previously, there is a notable increase in well-being events being arranged for carers. Both these types of direct and indirect support can often help carers find the information and support they need and help reduce carer loneliness and isolation.

Among the responses, there is little evidence of social enterprise or cooperative development, which we believe is an opportunity.

4.3 Future plans to support carers

Nine local authorities responded that they have, or are working towards, the development of a carers strategy. However it is not clear from the local authorities who do not have a carers strategy, what they intend to put in place for the medium and long term.

Carers Wales hopes that carers strategies consider how carers are supported across local authority departments including social services, transport and housing.

Most local authorities indicated that they are continuing to work on the three Welsh Government national priorities for carers:

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

4.4 Barriers and obstacles

We also asked Local Authorities to comment on the barriers and obstacles in places that are preventing them from successfully rolling out of the act. They can be summarised as follows;

Funding and capacity

Most indicated that funding continues to be the main issue, with local authority budgets being inadequate to meet demand. Persistent under-funding of social care means there is a lack of social work capacity leading to delays in carers assessments and reviews. Added to this, the short-term nature of Welsh Government funding allocations and uncertainty around future funding stifles progress, innovation and commitment to enable services to be commissioned and planned effectively. Some asked that funding streams are ring-fenced for carers and others raised frustrations that existing funding streams are more complicated than they need to be.

Performance indicators

Local Authorities requested clearer guidance on performance indicators and commented on the need to develop comprehensive and accurate reportable information on carers. Many local authorities recognised a need for better internal reporting and data capture systems.

Staff awareness

There is a need to continue raising staff awareness of the rights and needs of carers across the health and social care sector and with carers themselves. This would help staff support individuals to identify themselves as carers and where they can go for IAA.

Communications with carers

Staff involved with undertaking assessments feel that the terminology is a barrier. The very word 'assessment' makes carers feel they will be judged on the quality of the care they provide. This is thought to be one of the main factors behind the high rate of people declining the offer of an assessment.

In addition, the expectation is that an assessment will meet all of the needs of a carer, which is not always possible. When a carer's needs can be supported earlier on, it may negate the need for an assessment.

Partnership working

Working in collaboration with local health boards and other local authorities was identified as being important for an integrated and strategic approach. However the complexities of partnership working require time and investment to develop and embed.

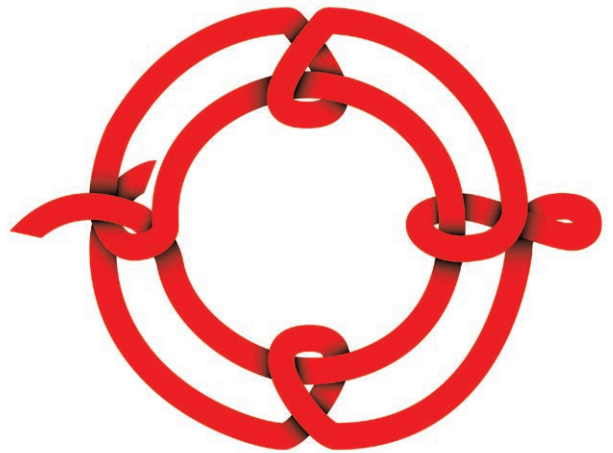
Voice and control

Co-production requires development time and support for it to be meaningful. Having the capacity to do this is challenging.

5. Local Health Board Feedback

We requested information from local health boards, due to the importance of the Regional Partnership Board's integration agenda in line with Welsh Government's 'Together for Health' strategy. They have received funding provided through the Integrated Care Fund, Transformation Fund and the recurring funding allocations to meet Welsh Government's three national priorities for carers.

We asked local health boards to provide information on how they are planning with local authorities, the third sector and others to support carers now and in the future. Carers Wales received information from all 7 local health boards for 2018/19 and we would like to thank them for their responses.



5.1 Funding to support carers

In light of the Intermediate Care Fund, the Transition Fund and other funding sources allocated to local health Boards, we asked them to identify what funding has been allocated to services/support for unpaid carers in 2018/19 and 2019/20.

All local health boards responded to this question. The funding has been used to fund and commission a range of different approaches and collaborations to meet carers needs. A summary is given below, however, the complete responses can be accessed on our website. Some of the examples of integrated working have been listed in the previous local authority section.

Local Health Board	Examples given
Aneurin Bevan	<ul style="list-style-type: none"> • Employed implementation staff team • Young carers in School Award Programme • Small Grant Scheme • GP practice training • Home First Discharge model • Introduction of Employers for Carers • Carer Engagement
Betsi Cadwalader	<ul style="list-style-type: none"> • 3 full time hospital facilitator posts in three acute hospitals until March 2020 • Primary Care Facilitator posts to work with GPs • Pilot of Young Carers in Schools programme
Cardiff and the Vale	<ul style="list-style-type: none"> • Young carers in schools accreditation project • Health and social care accreditation scheme • Carers Centre pilot • Patient Experience Team undertaken training to encourage staff to recognise carers and involve them in discharge planning
Cwm Taf	<ul style="list-style-type: none"> • No specific carers projects, however they reported that carers benefit from the other ICF schemes in place • Support for Cwm Taf Stroke Group and a Young Adult Carers Group in Rhondda Cynon Taff • Developed an A-Z Guide as a source of information and advice and a leaflet for Young Carers (developed by young carers themselves) • Adult carers residential weekend • Carer provider network
Hywel Dda	<ul style="list-style-type: none"> • A Carer Resilience and Well-being Project in Ceredigion • Carers Information and Assessment Officer in Carmarthenshire • A range of information, advice and assistance services to carers
Powys Teaching	<ul style="list-style-type: none"> • (The only local health board to submit a joint Track the Act response with the local authority) • Co-production of a respite project • Carer representative support for attending meetings • Outsourced carers services
West Glamorgan	<ul style="list-style-type: none"> • Carers Centre/Service staff in Bridgend, Neath Port Talbot and Swansea • Regional Carers Co-ordinator post • Carers Events • GP Accreditation scheme resources • Young carer projects • Single point of contact/triage project for carers

As can be seen there are examples of good practice in primary and secondary health settings across Wales. However, what is available to a carer in each area is inconsistent. Furthermore, many projects are, or have been, running on time limited funding. We are concerned that if continuation funding is not provided, or services are not mainstreamed, then projects will cease and carers will miss out.

We are also concerned that annualised funding and the relatively quick turnaround to deliver projects within the financial year minimises the ability to consult with carers and the opportunity to meaningfully co-produce.

The Carers Strategies (Wales) Measure 2010 placed a legal duty on local health boards to ensure the identification of carers in health settings and provide them with ‘timely appropriate information and advice’. Since this Measure was repealed when the Act came into force the momentum to provide carers with information in health settings seems to have been diluted. We would like to see a responsibility for identifying and supporting carers to be reinforced.

5.2 Future plans and barriers to supporting carers

Many of the local health boards gave examples of how they are bringing carer’s considerations into their operational work and increasing profile. However, they voiced concerns regarding their ability to plan and develop services that support carers due to the annual funding allocation and lack of certainty surrounding all of the funding streams. It is also clear from some of the responses that it has an effect on the continuity of services and has undermined innovation. Added to this is the acknowledged increasing demand for services.

One health board recognised that some services for carers, including staff carer awareness training and providing information, advice and support needs to be subsumed into core activities and strategies but pressure on budgets and other priorities make this challenging.

The responses we have received for future planning from the LHBs lacked significant detail which is concerning when the Welsh Government’s vision in ‘A Healthier Wales’ is to provide care closer to home with the obvious implications that this may have on the ability of family carers to sustain a caring role without adequate support and services.

Added to this Carers Wales would like to see carers needs being considered in all elements of health funding and not just the yearly allocations.

6. Policy context

Carers Wales welcomes the level of interest in carers over the past year from politicians and public bodies in Wales.

Since our last report:

- the Ministerial Advisory Group on Carersⁱⁱⁱ met twice.
- the Welsh Assembly’s Health and Social Care Committee has gathered evidence and is concluding its inquiry on the *Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers*^{iv}. We await the final report.
- Wales Audit Office study and report on judging the effectiveness of the new ‘front door’ to social care, looking specifically at services for adults.
- A further £1 million Welsh Government funding was allocated to local health boards to deliver the three national priorities for carers
 1. Supporting a life alongside caring,
 2. Identifying and recognising carers and
 3. Providing information, advice and assistance.
- A Welsh Government public consultation on the Code of Practice to measure Social Services performance and improvement, including a new section on carers.
- Measuring the Mountain was awarded further funding for 18 months to expand on its work on people’s experiences of social care.
- Welsh Government commissioned independent research and evaluation of the Act.
- £50m Integrated Care Funding was announced in April 2018 to Regional Partnership Boards to support joined up working between health, social care, housing and the third-sector. Part of the £15m of this funding is being allocated to improve support for carers.
- The £100m Transformation Funding allocated to develop new models of health and social care to support key actions from the Welsh Government’s long term plan for health and social care “A Healthier Wales”.
- Welsh Government have revised and produced the annual ICF guidance to include a greater focus on carers.

i <https://gov.wales/adults-receiving-care-and-support-april-2017-march-2018>

ii Juggling Work and unpaid care – A growing issue (Carers UK, 2019)

iii <https://gov.wales/about/cabinet/cabinetstatements/2017/carerfriendlywales/?lang=en>

iv <http://senedd.assembly.wales/mgIssueHistoryHome.aspx?IIId=022518>

Our mission is to make life better for carers



We give expert advice,
information and support



We connect carers so
no-one has to care alone



We campaign together
for lasting change



We innovate to find new ways
to reach and support carers



Carers Wales
Unit 5, Ynysbridge Court
Gwaelod y Garth, Cardiff
CF15 9SS

T 029 2081 1370

E info@carerswales.org

carerswales.org



@carerswales



/carerswales

Carers Wales is part of Carers UK, a charity registered in England and Wales (246329) and in Scotland (SC)39307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX

ISBN: 978-1-912525-09-6
© Carers UK (Wales) 2019



Llywodraeth Cymru
Welsh Government