

Health and Social Care Committee - Inquiry into the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

1.0 Introduction

Carers Wales is part of Carers UK. Established in 1965, we have led the carers' movement for over 50 years. We are a responsive, expert charity, led by carers, for carers and with carers. As the UK's only national membership charity for carers, we are highly respected in our field – as a support network and as a movement for change. Since our inception, we have been campaigning with carers, transforming understanding and winning critical developments in carers' rights.

We welcome the Committee's inquiry into the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to unpaid family carers. We were also pleased to host a focus group with carers with your Assembly Communications Outreach and Liaison Officer.

Carers are not a homogenous group and will have different needs depending on their caring situation. In Wales according to the last census in 2011 there were 369,186 carers. Of these carers 87,173 were aged 65+ and 131,120 aged between 50-64.

Caring can take place in the context of relationships which may be positive but it is important to consider that this will not always be the case. Carers are generally linked to people by bonds of love, friendship and duty but they can also be bound by necessity, guilt and family pressure.

103,594 people in Wales according to the last census provide over 50 hours of care each week. People providing high levels of care are twice as likely to be permanently sick or disabled.

96% of annual care in Wales is provided by unpaid carers. The care they provide would cost £8.1 billion pounds a year in Wales if it had to be replaced by statutory services. It is crucial therefore that carers are properly identified, recognised and supported to continue to care.

There are 181,135 carers who are juggling work (including self-employment) whilst providing unpaid care in Wales. 100,260 carers work full-time and 54,480 work part-time. Many of these carers will be "sandwich carers" often with dual responsibility for looking after an elderly parent as well as children. They may also be caring at a distance.

The peak age of caring is between the ages of 45-64 when people have reached the peak of their careers and are valued members of staff.

By 2037 it is estimated that there will be a rise of 40% of carers in Wales meaning that there will be over half a million unpaid carers (518,322).

We welcome Welsh Government's continued commitment to carers and the Minister for Children, Older People and Social Care setting up the Ministerial Advisory group for Carers. We also welcome the Minister allocating specific additional money to the Integrated Care Fund specifically targeted at carers. We will however want to see open and transparent evidence of where the money allocated to carers has been spent and specifically how carers have benefitted as a result.

At implementation of the Social Services and Wellbeing Act, Carers Wales developed the 'Track the Act' programme to monitor delivery for carers. Briefing 1 covered the first six months, Briefing 2 related to the whole first year from April 2016 – April 2017 and Briefing 3 relates to the whole second year April 2017 – April 2018. All briefings can be found here:

<https://www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-briefings>

As part of the programme we undertake an annual survey of carers and request information from each Local Authority area in Wales. In briefing 3, for the first time we also asked for information from Local Health Boards. All the information we receive is published on our website.

The third Track the Act briefing can be found here:

<https://www.carersuk.org/files/section/5763/carers-wales-track-the-act-2018-final-140918.pdf>

In general we believe that the vast majority of the general population are unaware that the Social Services and Well-being (Wales) Act exists and what potentially it could mean for them.

2.0 Overview of Enquiry Question Responses

- The number of carers' assessments undertaken in Wales and how this has changed as a result of the Social Services and Wellbeing (Wales) Act 2014 and whether there is variation between local authorities;

Our 'Track the Act' research shows that data collection in each local authority area is different and therefore it is difficult to judge how many carers assessments are being undertaken. In addition, in some areas local authorities themselves complete the assessments and in others this service is contracted out e.g. to a third sector provider. We know from our research that in some cases not all completed assessments are being captured in data collection.

Furthermore, as a result of some local authorities using a 'What Matters' conversation approach, there is confusion about whether this constitutes an assessment and as a result is captured or not.

- The number of carers receiving support following a local authority assessment, including respite care, how this has changed since the Act came into force, and whether there is variation between local authorities;

Again, due to varying data collection, this is difficult to gauge. However, we do know that the vast majority of carers are not receiving an assessment or indeed being supported as a result.

- The extent to which local authorities are fulfilling their duties under the Act to provide information, advice and assistance to carers;

Our Track the Act research shows that this is varied and we believe the majority of carers are still not aware of, or are accessing the IAA service.

- Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;

The Population Needs Assessments that were produced hold a lot of information on carers at the local level. However, there is an issue of many carers not self-identifying as a carer and therefore data such as that collected in the Census is unlikely to be accurate.

- Broader Welsh Government policy on carers and how it should be developed.

We believe the three carer priorities identified by the Minister are appropriate. However they are very high level. The new Ministerial Advisory Group on Carers offers a good opportunity to drive forward carers policy to deliver the priorities.

3.0 Supporting Information

3.1 Provision of Information, Advice and Assistance.

Under the Act local authorities have a duty to secure the provision of a service to provide people with information and advice relating to care and support and information about support.

We are concerned that many carers who may be accessing first point of contact services in local authorities are not being identified and that staff are not adequately trained to recognise carers and give them the information that they need. This seems an opportunity missed and subsequently many carers miss out on appropriate advice and information, with significant consequences to their own health and well-being and their ability to juggle work and care.

As highlighted in our 3rd Track the Act briefing, there are a range of ways that local authorities provide or commission this service and a range of different approaches to provide information.

The provision of information to carers is a key part of the Act and we know from our research that when carers receive information they value it. Information is crucial to prevent carers reaching crisis point. This information should consider all aspects of a carer's life, including rights at work, benefit entitlement, local support and the right to receive a carers support needs assessment which is often key to receiving respite/replacement care services.

The data we have received from local local authorities to our information request for the period April 2017 – April 2018 indicates that each local authority operates differently to collect this data. Several local authorities were unable to provide any data due to the implementation of the Welsh Community Care Information System.

Carers Wales Track the Act research indicates that more and more people are seeing information from local authorities (but generally respondents to our survey had been caring for over a year). We are concerned that information is not reaching new and 'hidden' carers and local authorities along with their key partners should be taking a more proactive approach to reach out to carers and people in need.

From our research 'Missing out – The Identification challenge' (Carers UK 2016)

- Over half of carers (55%) took a year to recognise their caring role
- 24% took over 5 years

Some groups of carers, such as parent carers, mental health carers and distance carers take longer than average to identify their role. By not self-identifying, carers miss out on financial or practical support (or both). These carers would probably say "I'm just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a neighbour" and it is imperative that there should be a national awareness raising campaign by Welsh Government to reach out to these "hidden" carers to ensure that they know that there is information and support available to them.

Our research shows that the cost of remaining 'hidden' is significant:

- Half of carers (50%) said that missing out on support had an impact on their physical health
- Three quarters of carers (78%) suffered from stress and anxiety as a result of missing out on support
- For half of carers (52%) missing out on support impacted negatively on their finances
- 42% said missing out on support had caused them to give up work to care.

Almost half (47%) of respondents to Carers Wales State of Caring survey 2017 said that they had given up work completely to care.

Prevention is a key element of the Social Services and Wellbeing Act and local authorities should be doing more to reach out to carers in their communities to signpost them to the IAA service for help, assistance and assessment.

A carer at our Assembly Communications focus group said “People don’t understand or recognise the word carer, we need to use language people understand”.

There are ways that local authorities could reach hidden carers, such as through issuing local authority tax bills. This could be a relatively cost neutral way of local authorities reaching out to hidden carers and publicising their services. It may also be a way of developing a register of carers and finding out what sorts of services are needed to feed in to local population assessments. Reaching out in this way should not be a one-off process as there is a constant churn of carer turnover.

The Carers Strategies (Wales) Measure was repealed during the legislative process for the Social Services and Wellbeing (Wales) Act 2014 and new strategic planning duties were placed on Local Health Boards and Local Authorities to work together in the Future Generations Act. Two years into the Act we feel that a vital role has been lost within the NHS in identifying carers and signposting them to sources of support, including the local authority IAA services. For 4 out of 5 carers their first point of contact with any statutory agency is generally within a primary care setting¹. It is therefore vital that health has a responsibility along with local authorities to identify and signpost hidden carers.

Secondary care services also have an important role to identify and signpost carers in hospital and other secondary care services. In our State of Caring Wales 2017 report, we recommended that a new duty is placed on the NHS in line with the repealed Measure to put in policies to identify and signpost carers, promote their health and well-being. We would also like to see new measures put in place to put a duty on GP practices to identify and supporting carers. In our State of Caring report 2017 73% of respondents said that their GP know they are a carer but that they don’t do anything different as a result.

“Hospital service was not connected to the local authority. Had to badger people to get support. Left to get on with it for 8 months after my husband’s stroke having been sent home with meds and victim support number”

“Don’t know what help there is or where to get help from as I’m also disabled so my husband cares for me physically and I care for him as he suffers from mental health”.

Track the Act respondents 2018

A carer has also raised a concern about A Healthier Wales – Welsh Government 2018. In this report on page 7 it states “As part of working together to achieve our future vision, we need people to take more responsibility, not only for their own health and wellbeing, but also for their family and

people they care for, perhaps even for their friends and neighbours” the carers stated in her response to me that “This policy explicitly proposes increasing the responsibilities undertaken by carers”. Implementation will be critical, as it seems carers will be impacted.

According to Welsh Government statistics released for the period 6 April 2016 to 31 March 2017ⁱⁱ only 52759 adults received advice and/or assistance from the IAA Services in relation to their own care and assistance in accessing care and/or support.

From our Track the Act survey not all of the IAA services keep management information data on the number of carers making contact with the service which means that there is no mechanism in place to measure performance. From our information request responses from local authorities, it is apparent that there is clearly good practice in many areas but this is not translated across every local authority in Wales.

For those who responded to our Track the Act survey when carers do see information they generally find it useful. Track the Act respondent “*The information is out there if you look for it. Carers are often too tired to make that effort*”.

Where carers do reach the IAA service and are signposted, it is also not clear whether their needs are being met by external organisations. There appears to be no follow-up mechanism to record whether carers or disabled people have had their needs met or not. If needs have not been met and they would meet the eligibility criteria for services and/or support then those carers and disabled people will have fallen through the net.

In the Minister for Children, Older People and Social Care’s Written Statement on 24th November 2017, he committed to establishing a Ministerial Advisory Group made of key partners and identified 3 national priorities for 2018/19. These three priorities include:

- Identifying and Recognising carers as being fundamental to the success of delivering improved outcomes is the need to improve carer’s recognition of their role and to ensure that they can access necessary support
- Providing information, advice and assistance – it is important that carers receive the appropriate information and advice where and when they need it.

This is a positive step welcomed by Carers Wales. However, the rhetoric needs to be turned into reality and we hope that there will be new mechanisms put into place to measure progress against the money allocated to achieve these aims.

It is also worth noting that from our research “In the Know – The importance of Information for carers” that every year in Wales 123,000 people will start caring whilst another 123,000 will stop. Potentially these new carers will not self –identify and may miss out on vital practical as well as financial support which may mean the difference in carers remaining in or giving up work. It is vitally important that all statutory services embed the identification challenge into their work.

Those whose caring role ends can also be a vulnerable group. This is especially so for those carers who have been providing significant care for a number of years who are likely to have given up work, become socially isolated and have possibly developed ill-health conditions of their own because of their caring responsibilities. It is vital that service and information providers also consider this group of carers and ensure that they receive appropriate information and advice about any benefits they may be entitled to, entry back into the labour market, bereavement counsellors and social networks to help carers move forward and alleviate feelings of social

exclusion and isolation. Equally education providers also have an important role to play to help carers to re-skill and prepare for re-entry into the labour market.

3.2 Advice

Most carers who completed our Track the Act survey 2017-2018 61% had not received advice that would help them in their role as a carer. This is disappointing given that the majority of respondents to this year's survey had been caring for over a year with significant caring roles. Where carers did receive advice 62% said they received it from someone working for the third sector and 32% from the local authority. Generally they found the advice helpful. Track the Act respondent. *"So glad Carers Wales gave advice about what to claim, prior to this we were not receiving benefits which we were entitled to"*.

By carers receiving appropriate advice about benefits that they and the person they care for may be able to claim can make a huge difference to their finances and health and well-being. It can make a difference in whether they turn to statutory services for help or buy in services externally themselves to meet their need.

3.3 Assessment of need

According to Welsh Government statistics for the period 6th April 2016 to 31st March 2017 only 6207 assessments for support for carers were undertaken, of these only 1823 carers received a support plan. We have not had sight of Welsh Government statistics for the period 6th April 2017 to 31st March 2018 yet.

We know that not all carers will want or need an assessment. This is largely dependent on the individual and how they are coping with their caring roles. However, we believe at the outset if carers are accessing information, advice and assistance they should be told about this right and what benefits there may be to having an assessment.

Findings from our Track the Act survey 2017-2018 found that 54% of carers said that they had not been offered, requested or had a review of a current carer's needs assessment. For those that were offered or requested an assessment, 37% did not meet the eligibility criteria for services. Given that the vast majority of respondents to this year's survey had been caring for over a year with significant caring responsibilities this is extremely disappointing.

It is also disappointing because often the Carers Needs Assessment is the mechanism that opens up opportunities for respite or replacement care which supports the carer to be able to continue in their caring role, to have a life outside caring and to be able to look after their own health and well-being. The effects of not having a break from caring is shattering and carers are desperate for some time to themselves to be able to sleep, recuperate.

The right to a carers needs assessment is a key element of the Act. Carers have a right to an assessment in their own right and local authorities have a clear duty to promote this. There is an issue with the language used in relation to "Carer Assessment". Often carers will consider this an assessment of their ability to care rather than an assessment of what support needs the carer may have. This language can put many carers off requesting an assessment.

One carer who attended the focus group with Assembly Communications said *"Carers Needs Assessment have less value now than before the Act. Local authorities were previously using a Carers Needs Assessment form, now it's a 'What matters' form which is 2 sides of A4. What message does this send to carers?"*

Another carer at the same focus group said *“I didn’t know I was being assessed and I felt that a ‘what matters’ conversation made it easier to not implement support”*.

A further comment was made that *“Social workers are distressed about what they can’t do because of austerity/cuts. They feel the most loathed profession”*

Many carers may be being assessed as part of the ‘whole approach’ in the disabled person’s needs assessment. If this is the case, then the carer should be informed that their needs have been assessed or are being assessed as part of the disabled person’s care plan. As per the Act, the practitioner should ensure the carer’s willingness and ability to care and caring responsibilities are properly negotiated. It appears that if carers are being assessed in this way, that this data is often not being captured.

Those carers who are being assessed in the ‘whole’ approach should be informed that as well as being assessed as part of the disabled person’s needs assessment they also have a right to a separate assessment of their support needs should they feel that the practitioner has not adequately taken into account their needs. It is often difficult for carers as part of the ‘whole approach’ to articulate their needs for fear of upsetting their loved one. An example would be where a daughter is looking after a parent and does not want to undertake personal care.

From our Track the Act survey 2018 it is clear that the way that Carers Needs Assessments are approached by local authorities differs vastly across Wales, along with the time it takes to receive an assessment. Given that the Act is focussed on prevention, it is not acceptable that many carers are waiting for long periods of time or are being declined.

“Assessment took a year – still no result six months later”

“Requested Carers Assessment but was declined”

There still seems to be confusing about whether a ‘what matters’ conversation is an actual assessment.

A carer has told us *“I didn’t know I was being assessed and I felt that a ‘what matters’ conversation made it easier to not implement support”*

Another carer said *“What value is being placed on carers? ‘What matters’ is not a lengthy assessment which used to ask us the right questions, it gave up an opportunity to share information”*

Some local authorities will offer a pre-assessment ‘What matters’ conversation, others will send a pre-assessment form in the post, some local authorities commission out the service to third sector organisations whilst others will have dedicated officers in post. We welcome Welsh Government instructing Social Care Wales to identify best practice in relation to this process and we would hope that local authorities will roll out the recommendations in due course.

We are also concerned that the rights afforded to people under the Human Rights Act are not properly being considered at the Information, Advice and Assistance service or in the carers or disabled person’s needs assessments. In particular, carer’s health and well-being are not being taken into account. Often carers are putting medical procedures on hold with consequences for their health. *“I need two knee replacements but get morphine instead to cope”*. In extreme cases, carers have delayed emergency medical treatment, which could cost them their lives. It is imperative that assessments are therefore done in a timely manner and that the information,

advice and assistance service ask carers whether they have any concerns about their health that required medical intervention so that services can be put in place to meet need.

3.4 Broader Welsh Government Policy on Carers

We have made various recommendations to Welsh Government and local authorities in our Track the Act briefing 3. In particular, that ‘there needs to be an honest assessment of the obstacles and barriers currently in the system which is frustrating the successful roll out of the legislative aim of the Act’. Carers need to be supported and have the information and assistance to understand the system and know where they can go to get help.

We also recommend that Welsh Government change its approach from annual funding allocations to longer term grants to enable longer term planning and sustainability of carers services.

There needs to be robust data collection as part of Social Services Performance Measure requirements from local authorities and this should be done in collaboration with others, including members of the Ministerial Advisory Group for Carers to set out a clear mandate and unambiguous approach to ensure that effective data is collected.

Welsh Government should fund a national awareness programme to help carers identify and promote their rights to Information, Advice and Assistance and to their rights to receive carers assessments.

ⁱ Carers Strategies (Wales) Measure 2010

ⁱⁱ <https://gov.wales/docs/statistics/2017/171031-adults-receiving-care-support-2016-17-en.pdf>