



<http://www.cost-of-living.net/caring-for-carers/>

by **PAUL WHYBROW & KIM HEYES** Jun 15, 2016



*Image: Shutterstock*

Did you know that the 6<sup>th</sup> and 12<sup>th</sup> of June was Carers Week? A range of events and activities taking place all across the UK celebrating the work of carers and raising awareness of the challenges they face. It is important to celebrate and recognise the fantastic and often hidden work of the men, women and children who, without payment, provide help and support to a family member or friend who simply could not manage without it. The burden of this work is considerable, which if it were it to be paid would add up to around **a staggering £132 billion per year**. If you add to this the fact that unpaid care is often stressful and sometimes quite isolating, you'll agree that carers deserve recognition and support.

The 2014 Care Act was described as the biggest 'shake up' of social care in the UK since the 1950's. It promised that it would give carers the same entitlement to care as the people they care for and that the individual's wellbeing and choice would be paramount. Sounds great and yet, speaking to carers and local authorities, no one seems quite sure about what has actually changed. So why have so few people benefitted since its launch on 1<sup>st</sup> April 2015, and why are so many people still struggling to access appropriate health and social care?

One of the fundamental changes to the Care Act is ceding greater responsibility to Local Authorities to inform, assess and manage the support of those that need them. Carers are eligible for a needs-assessment and allocation of a Personal Budget that they can, in theory, spend as they see fit. However, even the organisation behind this idea has noticed problems reporting that **"nearly half of respondents felt their quality of life had**



reduced, and 30% experienced a reduction in choice and control". The following example is a case study of a Local Authority review of the Care Act implementation.

*Susan cares for her husband Derek. They are both in their late 60's. Derek has severe mobility problems due to arthritis and a heart problem. He can manage to get out to the shops with the help of Susan and his wheelchair. Despite also suffering with arthritis, Susan provides all the domestic care for Derek. However, she has recently started to struggle with household chores and finds it difficult to lift the wheelchair in and out of the car. She says that some days the shopping has stayed in the car because the effort to get her husband to and around the supermarket has left her exhausted. Susan is upset by this change in herself and scared that, if she asks for help, they may take her husband to a home.*

This story is not uncommon. Many carers only want to continue to provide care for their loved one without relying on others. They may feel upset and anxious about asking for help even when it's clearly needed. In practice, few people are actually being "needs-assessed" and Local Authorities are failing to inform those who are eligible.

Asking for help can be difficult for those who provide care for loved ones. Parents of children with care needs might worry about contact with social workers, scared that their own care provision may be judged and found unsatisfactory. Consequently, those who are most in need of help can be liable to underestimate their requirements. To counter this, there is a need for some level of external assessment. But this then forms a feedback loop regarding judgements from professionals. It is perhaps little wonder that Local Authorities have been unable to inform and give assessments to those that need them, as many are struggling just to keep up with the reassessments of those already receiving support. Waiting times for carers assessments can take 6 months, and social workers report a constant need to 'catch up' with a result that many carers are already at a crisis point before they can be seen.

So surely those carers who have actually received assessments are at least benefiting from the self-directed care and personal budgets promised by the Care Act? Sadly herein lies the central betrayal of the policy, which in fact reduces and depersonalises support.

*Lauren cares for her adult son who has mental health problems, and he has also been helping to care for her. Lauren has been using an alternative therapy for over 20 years as part of her recovery from final stage*



*cancer. The NHS and local authority had been paying the cost of this treatment, on which Lauren relied physically and psychologically. However, after her assessment for care needs, she was told that the funding would no longer be available. Her treatment has been stopped without any consultation. The effect on Lauren's wellbeing is extremely negative, and this also affects her son's mental health in what has become a vicious cycle.*

This is another real life case taken from the notes of a Local Authority. Again, this is not unusual, Carers UK report, as a result of the assessments, only 35% felt that they had been offered the support that they needed, and 59% of people say that, after their assessment, **they are now worse off financially**. To reach the decision to discontinue Lauren's care took six months, an MP, several charities, an advocate and an NHS representative. Because no one would take ownership of the issue, the decision-making process was expensive and lengthy. Despite the rhetoric of individual choice and wellbeing, the reality is that, much like before needs are assessed by the Local Authority. The reforms have led to more fragmented services. What's more, the definition of need is quite literally based on the (limited) resources available to meet them.

As the shortcomings of the Care Act have become apparent, advocates say the problem has been in its implementation; that Local Authorities have yet to fulfil the responsibility of informing, assessing and managing support for those that are eligible. Others are more critical saying that the fundamental flaws in the Care Act suggests it serves only to disguise the perpetuation of an under-resourced, dysfunctional system that **actually depersonalises care**. The key point here is that, even if Local Authorities were to inform better and reach out to those people who desperately need help, officially recognising those needs and allocating a personal budget is wholly dependent on available resources. It is no wonder that the Care Act was able to provide promises of person-centred care and the paramount issue of wellbeing, while it is simultaneously placing the responsibility of delivering on those promises to Local Authorities.

Time will tell whether carers come to see some of the wonderful promises made by the Care Act 2014, or whether the reforms merely serve to outsource responsibility for the shortage of help and support. It will take years before we see the benefits to this, and at which point they will probably change the legislation again.

**About the Authors:** **Paul Whybrow** is a medical sociologist interested in the organisation of healthcare and combined research methods. He works as a Senior Research Associate in Qualitative at Research, at the School of Social and Community Medicine, University of Bristol. **Kim Heyes** is a part-time associate lecturer and research project manager at MMU in Cheshire. She has taught in Abuse Studies, Criminology, Sociology,



Globalisation and Clinical Psychology. Previous to this post she has worked as a community mental health support worker for adults and older people.