

Carer Support: Ten years after the Care Act

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1. Introduction

The 2014 Care Act was deceptively simple in its key purpose to:

"make provision to reform the law relating to care and support for adults and the law relating to support for carers." (HM Government, 2014)

This central objective arguably fails to convey the significance of this major legislation and its potential to be groundbreaking in the scale of its ambition. The Act (introduced under the Coalition government) was in large part the response to the Dilnot Commission Report on the funding of long-term care (Dilnot Commission, 2011), and established national eligibility criteria for social care, and a 'lifetime cap' on the amount anyone would need to pay for their care (set initially at £72,000). However, the Act failed to be fully implemented, with the cap on costs (Part 2 of the Act) initially delayed until 2020, and subsequent plans for a revised cap (£86,000) to be introduced from October 2023, before being put back again by a further two years.

Despite the frustrations with the delays to the funding reforms, and the continuing challenges of finding a solution to the fair funding of social care, the Act was also concerned with other important developments. Two features are of particular significance:

- The general duties of the local authority to promote individual wellbeing.
- Parity of esteem for carers and the people they support.

The concept of 'wellbeing' is broadly understood internationally and the OECD, for example, has developed metrics for a 'better life index', and attempted to take account of what matters to people, and to look beyond GDP and material wealth (Stiglitz, Fitoussi, & Durand, 2018). In the Care Act the 'wellbeing principle' was also broadly defined and applies to all the functions under Part 1 of the Act, meaning that whenever a local authority makes a decision about a person, they must do so in ways that promote their wellbeing (Local Government Association, 2014). This recognises the importance of addressing physical, mental and emotional needs, as well as supporting personal dignity and enabling people to exercise control over their daily life. This also includes attention to people's multiple roles and responsibilities (including participation in employment, education, training and leisure), as well as their social and economic wellbeing and relationships. The wellbeing principle was welcomed for the scope to respond much more widely to people's needs, and to do so in flexible and responsive ways that were not always about a service or eligibility. These wellbeing considerations apply equally to people with care and support needs, and to the support needs of their carers, with acknowledgment of the importance of achieving a balance between the needs of both parties.

The Act gave carers entitlement *in their own right* to an assessment of their needs, whether or not the person they care for meets eligibility criteria for care and support. In addition, the Act brought in a duty for local authorities to meet carers' assessed eligible needs for support. A new duty for local authorities to provide information and advice relating to care and support for adults, and support for carers, was also widely seen as a positive development.

The Act also included a requirement for local authorities to have regard to the importance of preventing, delaying or reducing needs for care and support, including carers' support needs. The statutory guidance on the Care Act included an example of prevention for carers in these terms:

"This could also include helping carers to continue to care, enabling them to have a life of their own alongside caring, to have breaks from their caring responsibilities, develop mechanisms to cope with stress associated with caring and awareness of their own physical and mental health needs, e.g. emotional support or stress management classes." (Department of Health, 2014, p. P.14)

2. Implementation of the Care Act

Ten years on from the Care Act entering the statute books may be an appropriate point in time to take stock of what has – and has not - been achieved. We are focusing here particularly on what difference the Act has made for carers, both in principle and practice, drawing on recent work on carer support undertaken at IPC, but also drawing on a wider body of research and analysis.

Burn et al comment that it is clear that most of the goals of the Act have not been achieved:

"The Act's funding reforms were abandoned, the number of carers' assessments has fallen below expectations, individualised care funding has stalled and investment in prevention has been deprioritised." (Burn, Redgate, Needham, & Peckham, 2024)

The reasons for limited achievement are complex but have been attributed by Burn et al to the impact of short-term austerity; longer term funding uncertainty, and risk averse practices by local authorities (Burn et al., 2024). Despite these limitations, Burn et al assert that:

"The foundational principles of the Act – a commitment to wellbeing, prevention, and reforming the funding of care – continue to shape care policy, though there is still uncertainty as to how the social care system will realise these foundational principles." (Burn et al., 2024, p. P.58)

A detailed examination of the impact of the Act on carers described it as "a combination of conceptual achievements and practical challenges" (Fernandez, Marczak, Snell, Brimblecombe et al., 2020). Despite greater clarity over carers' rights, the resource pressures on local authorities were seen as a significant limitation on ambition and delivery.

Despite these shortcomings, there *have* also been positive impacts. Certainly, the expectation that greater information, and the right to an assessment would lead to more carers identifying themselves and seeking support stimulated local authorities to develop stronger partnerships with provider organisations, particularly with third sector carer organisations who have been commissioned to deliver carer support, as Fernandez et al found:

"These partnerships led to a much greater involvement of the local voluntary sector in the organisation and delivery of carer support, and several carer organisations were given the lead responsibility for case finding and for carrying out carer assessments. We found less evidence of partnerships with the NHS." (Fernandez et al., 2020, p. P.30)

Although the aspirations of the Care Act were to support carers *in their own right*, the impact of the reality of resource pressures on local authorities has undermined this and failed to lead to greater support for carers, and indeed means that "formal care systems are likely to still approach carers as a resource" (Marczak, Fernandez, Manthorpe, Brimblecombe et al., 2022).

Our own recent evaluation of carer support for Norfolk County Council similarly highlighted the salience of third sector support for carers, but also underlined the relative absence of a joined up and integrated approach to supporting both the carer and the cared for person as a 'dyad' rather than as separate 'cases', with a lack of communication or visibility between local authority and third sector systems to promote integration. Focusing principally on providing a universal offer for carers (primarily based around information and advice and low-level support) was also in tension with the needs of carers with higher level and continuing needs for support. A major concern to avoid 'carer breakdown' was also driven by a motivation to realise cost savings for adult social care, but potentially at the price of increasing the demands made on carers.

3. The impact of Covid-19

The story of the implementation of the 2014 Care Act is still unfolding, and alongside the well-documented resource pressures and political uncertainties that have frustrated the realisation of initial objectives and vision for change, another major – and unforeseen – variable must also be considered. The impact of Covid-19 on social care in general and on carers in particular is still being assessed, but it has undoubtedly been substantial. As Forrester-Jones has observed, for example, there is a long way to go before the Care Act objectives are fully realised "with Covid-19"

only exacerbating structural, financial and support problems already in existence" (Forrester-Jones, 2021, p. P.111)

With the introduction of national lockdowns in March 2020, and the suspension of many services, the demands on unpaid carers intensified while many more people became carers because of the circumstances of the pandemic (Carers UK, 2020a, 2020b). At the same time, however, carers were largely absent from the policy response or political discourse (Dunn, Allen, Humphries, & Alderwick, 2020).

There is a growing research literature exploring the impact of Covid-19 on caring (Aker, West, Davies, Moore et al., 2021; Evandrou, Falkingham, Qin, & Vlachantoni, 2020; László Árpád, Zsuzsa, Virág Erzsébet, Paolo et al., 2021; Moultrie, Mallion, & Taylor-Page, 2024), and as Linden et al have remarked,

"There is consensus within the literature that the Covid-19 pandemic had an adverse impact on family carers' mental health and burden of caring responsibilities." (Linden, Leonard, Forbes, Brown et al., 2023, p. P.10)

At the same time, it is also acknowledged that despite the challenges brought by the pandemic, for some carers there were also opportunities, and for services and support to be reconfigured differently in ways that could be of greater value. Online and digital support, for example, emerged as a necessity but proved to be particularly valued in the opportunities for peer support for otherwise isolated carers. Other research has similarly underlined the value of "just checking" phone calls to carers during the Covid restrictions (O'Rourke, Pentecost, van den Heuvel, Victor et al., 2023). Nonetheless, these new approaches also exacerbated areas of inequality and social exclusion:

"...the normalisation of online support is infeasible without systematically addressing barriers relating to poverty and financial disadvantage, access to and literacy in digital and information technology. Particular disparities are apparent in the availability of cost-effective and reliable internet provision." (Linden et al., 2023, p. P.11)

In addition to the direct impact of Covid-19 on carers and those they care for, particularly carers of people living with dementia, Aker et al have commented on how the pandemic has highlighted significant gaps in the provision of social care for these groups (Aker et al., 2021). A further consequence of Covid-19 was the increased reluctance of carers to seek help because of their fears of what might happen to their relative, and not wanting to 'burden' the NHS (with particular alarm during the pandemic about the risks of entering either a hospital or a care home because of the high rates of covid infections and deaths). There may be a residual and long-lasting impact of such concerns resulting in carers providing more support without help for longer durations, and this would add to the pressures that carers are already experiencing in getting access to support (ADASS, 2023).

4. Conclusions

The insights into the impact of Covid-19 on carers may prove to have an accelerating effect on a wider understanding of carers' needs and what works best in supporting them. Certainly, the conclusions about the negative consequences experienced by many need to be understood and to inform the evolution of policy and practice.

Although our starting point was to consider the balance sheet of what has been achieved by the Care Act, we have recognised above that policy and implementation have not stood still over the last decade. There have been a range of factors that have made implementation more challenging, particularly around the pressures of austerity and public spending constraint, which were then compounded by the unprecedented consequences of the global pandemic. We have not yet entered a 'steady state' and indeed it is likely that the turbulence and unpredictability of the policy environment is the 'new normal' context for social care and wider public policy.

Much of the optimism which greeted the Care Act a decade ago has now dissipated, along with the hope for real and immediate change for carers. But despite the partial implementation of the Act, and fewer positive outcomes than might have been anticipated, the underlying principles and values of the Act (wellbeing, prevention, personalisation, parity of esteem) endure. The challenges and financial pressures for local authorities continue to cast a long shadow, but recognition of carers and the importance of appropriately supporting them are firmly embedded in the policy and practice narrative. This is not the time to dismiss the Care Act as 'a failure' but rather to focus on how best to ensure the key principles achieve meaningful translation into carer support and choice. The most positive ways forward are likely to reside in genuine partnership with carers (rather than treating them as a resource to save demands on the public purse), and in models of support which address the needs of caring dyads coherently rather than incidentally. As national policy initiatives continue to recognise the importance of carer support (notably through the Better Care Fund and the Accelerated Reform Fund), it is essential they are framed around the aspirations and principles of the Care Act, and finally enable delivery to be fully realised.

5. References

- ADASS. (2023). Autumn Survey Report 2023.
- Aker, N., West, E., Davies, N., Moore, K. J., Sampson, E. L., Nair, P., & Kupeli, N. (2021). Challenges faced during the COVID-19 pandemic by family carers of people living with dementia towards the end of life. *BMC Health Services Research*, 21(1).
- Burn, E., Redgate, S., Needham, C., & Peckham, S. (2024). Implementing England's Care Act 2014: was the Act a success and when will we know? *International Journal of Care and Caring, 8*(1), 47-63.
- Carers UK. (2020a). Caring behind closed doors. Forgotten families in the coronavirus outbreak. London: Carers UK
- Carers UK. (2020b). Caring behind closed doors: six months on. The continued impact of the coronavirus (Covid-19) pandemic on unpaid carers. London: Carers UK
- Department of Health. (2014). Care and Support Statutory Guidance.
- Dilnot Commission. (2011). Fairer Care Funding: The Report of the Commission on Funding of Care and Support. London.:
- Dunn, P., Allen, L., Humphries, R., & Alderwick, H. (2020). *Briefing: Adult social care and Covid-19. Assessing the policy response in England so far.* Health Foundation
- Evandrou, M., Falkingham, J., Qin, M., & Vlachantoni, A. (2020). Older and 'staying at home' during lockdown: informal care receipt during the COVID-19 pandemic amongst people aged 70 and over in the UK. *SocArXiv*.
- Fernandez, J.-L., Marczak, J., Snell, T., Brimblecombe, N., Moriarty, J., Damant, J., Knapp, M., & Manthorpe, J. (2020). Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention. Care Policy & Evaluation Centre, LSE, NIHR Policy Research Unit in Health and Social Care Workforce.
- Forrester-Jones, R. (2021). Older carers of people with learning disabilities: their experiences with local authority assessment processes and personnel. *Tizard Learning Disability Review, 26*(2), 105-113.
- HM Government. (2014). Care Act 2014. TSO.
- László Árpád, K., Zsuzsa, S., Virág Erzsébet, A., Paolo, F., Sabrina, Q., Marco, S., Giovanni, L., & Cristina, G. (2021). Impact of the COVID-19 Pandemic on Family Carers of Older People Living with Dementia in Italy and Hungary. *Sustainability*, 13(7107), 7107.
- Linden, M., Leonard, R., Forbes, T., Brown, M., Marsh, L., Todd, S., Hughes, N., & Truesdale, M. (2023). Experiences of UK and Irish family carers of people with profound and multiple intellectual disabilities during the COVID-19 pandemic. *BMC Public Health*, 23(1).
- Local Government Association. (2014). Get in on the Act: The Care Act 2014.
- Marczak, J., Fernandez, J.-L., Manthorpe, J., Brimblecombe, N., Moriarty, J., Knapp, M., & Snell, T. (2022). How have the Care Act 2014 ambitions to support carers translated into local practice? Findings from a process evaluation study of local stakeholders' perceptions of Care Act implementation. *Health & Social Care in the Community*, 30(5), e1711-e1720.

- Moultrie, E., Mallion, J. S., & Taylor-Page, C. (2024). "The Pandemic is Just Happening on Top of a Pandemic for Us". Unpaid Carers' Experiences of Lockdown in the UK: A Thematic Analysis. *Journal of Long Term Care*.
- O'Rourke, G., Pentecost, C., van den Heuvel, E., Victor, C., Quinn, C., Hillman, A., Litherland, R., & Clare, L. (2023). Living with dementia under COVID-19 restrictions: coping and support needs among people with dementia and carers from the IDEAL cohort. *Ageing and Society, 43*(10), 2424-2446.
- Stiglitz, J. E., Fitoussi, J.-P., & Durand, M. (2018). Beyond GDP: Measuring what counts for economic and social performance.