NIHR | Policy Research Unit
Older People and Frailty

The impact of Care Act Easements on co-resident carers over 70 looking after partners living with dementia

Webinar: NIHR Policy Research Units and Social Care

5th April 2022

Project team: Phil Drake, Debbie Price, Neil Allen & Jayne Astbury

University of Manchester

This presentation presents independent research funded by the National Institute for Health Research Policy Research Unit in Older People and Frailty. The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. Policy Research Unit Programme Reference Number PR-PRU-1217-21502.

The ‘easements’

The Coronavirus Act 2020 included the unprecedented power for local authorities to temporarily suspend the majority of their adult social care duties required under the Care Act 2014. These suspensions were known as “easements”

Eight local authorities enacted Stage 3 or Stage 4 easements in April 2020:

- Middlesbrough [ended 22 April 2020]
- Sunderland [ended by 18 May 2020]
- Birmingham [ended by 18 May 2020]
- Staffordshire [ended by 26 May 2020]
- Coventry [ended by 1 June 2020]
- Warwickshire [ended by 1 June 2020]
- Derbyshire (Stage 4) [ended by 9 June 2020]
- Solihull (Stage 4) [ended by 6 July 2020]

Project Overview

Primary Objective

- To investigate the impact of easements on this group of carers and those responsible for safeguarding within local authorities

Workstreams:

- Semi-structured interviews with 48 carers (24 easement areas/24 non-easement areas)
- Semi-structured interviews with 20 Principal Social Workers/Safeguarding Leads
- Survey (target of 500 responses)
- Legal analysis

Carer Advisory Group

Where we are now

- Interviews completed:
  - 20 local authority PSW/SL interviews (6 easement/14 non-easement) *[May to December 2021]*
  - 44 (/48) carer interviews (split between easement and non-easement) *[May 2021 to March 2022]*
- Survey in the field, closes 31st May 2022 (aiming for 500 respondents)
- **Today**:
  - Some findings from analysis of local authority and carer interviews relating to carer needs
  - Some legal issues arising
  - Next steps

NIHR | Policy Research Unit Older People and Frailty

Local authority actions and carer needs

- **Similar across local authorities regardless of easement status**

Assessments

- Care Act assessments to virtual/telephone [recognised as unsatisfactory, cf Mental Health Act Assessments after legal challenge Jan 21]
  - Loss of the doorstep test
  - No eyes on households where unmet needs, neglect or abuse might be taking place
  - Circumstances of phone-calls not known
- Reviews not in person [in at least one easement area, reviews stopped]
- General social work face to face visits stopped except in the more extreme cases

In-home care stopped in many cases

- Often, but not always, at the request of the couple
  - Real and present dangers of allowing carers in to put them at risk of serious illness/death (risks to older people with complicating conditions being communicated daily by government)
  - Carers often young, moving from home to home, different carers every day, no or variable PPE, potential asymptomatic spread
  - Perception by recipients that poor quality care being received (so might as well stop)
  - Without recipients declining to allow carers/other help in, some local authorities would have been compelled to enact easements
  - Where care continued it was because needs were so great people felt they had no choice but to put themselves at risk
- Follow up variable, but mostly no or little follow up
  - Some local authorities made occasional welfare telephone calls, but many simply left for carers to self-refer in the future

We talked about having a carer coming in the morning just to help her get showered and dressed and that was arranged for February. But of our own volition we decided – because at that time it was still quite scary, you know, people didn’t know how it was being spread, one thing and another, so we delayed it.

They [carers] never missed a day, they wore masks, and we just got on with it…we couldn’t have managed without it, **I mean we’d no choice really**

Day Centres & Respite Care

- Community initiatives – centres and offices closed
- Day Centres closed
- Groups moved online
  - Overall online is no respite for carers, often a greater burden
- Respite in residential homes reduced significantly except in more extreme circumstances
  - Respite isn't respite if it causes more stress than it relieves
- Unable to offer choice of residential care/respite

No respite…

I think that was the main thing, the loneliness. Not just being able to escape. I'm dreading the time when I can't leave him 'cos he's not safe. You know, I had a few accidents with burning things, and what have you, but I think it was the loneliness … the loneliness for me was the biggest impact

Well as a carer I've found it is harder because I haven't had – been able to get out and have what I call – it sounds very selfish, and I do feel selfish when I say it, but it hasn't enabled me to have the respite, have a break from it. … And you're not having a break from it, so it piles up and gets – and I think it gets – I think if it'd have carried on, I'd have popped, and I think I was getting depressed

I know that I qualify for four weeks' respite care a year. But I don't use it, simply because when he came back from the home, he was very dirty. His bottom was dirty. He hadn't had a shave for a week. He had been – they told me he'd just been pacing. He looked like a little old man, and he isn't a little old man. And he – he didn't want me to go – he wanted to be able to see me all the time. And I felt as though he felt abandoned so while ever I can keep him at home, I don't want him – I don't want to take advantage of these four weeks away.

The only arrangement was outside for fifteen minutes a week, once a week. That was the difficult – so you go through all the emotions of guilt and is she all right and so on, but on reflection, I needed it. … I got her back after the two weeks. So a mix, really. It wasn't, you know, A1 because I was thinking, from [partner],'s sort of perspective, that she's in a different environment. Are they looking after her? I can't access her. I can't check, and so on. So, you know, there was anxiety there. It wasn't a sort of total two week rest, as indeed it should have been, but at least it gave me an opportunity to get things that I'd not been able to

Where respite offered it was often no or nut much of a solution

Online provision could be a substantial burden to carers

You know, so it’s all right saying, oh yes computers are this and that, yes they are for people that can use them and people that can see to use them. But if you’ve got dementia and mental health problems, you try learning the computer when you’re seventy odd, it’s not that easy…It’s not a good alternative, not at all

Very high social risks in seeking help

- If people could no longer cope, they risked:
  - Not being allowed to see their partner
  - Being a sitting duck for Covid infection
  - Very rapid deterioration
  - Death, if Covid got into the Care Home, which was happening at frightening proportions
- Fear and lack of trust for some
- Stakes exceptionally high
- Concern about losing control: decisions taken out of their hands (e.g. not being able to return home from care home respite)

And two of our friends, I say, their husbands went in for respite and unfortunately it was when everything went into lockdown, and they've never come out. So, the home said, you know, they are still alive, but the home said well, really they've deteriorated, because they couldn't see family or anything. And, you know, they just weren't fit to go home. So, I'm not prepared to let that happen.

Quality and consistency of care provision

- Contractors and care homes operating with skeleton crews, staffing challenges
- For some carers: quality of care was a real concern
  - For some, care was poorly suited to need
- Local authorities found they had little control over what was provided
  - Increase in self-neglect
  - At least one case reported to us of domiciliary care services neglect such that it led to formal review
- Direct payments put forward as a solution
  - But privately recognised as not a solution for many in this service user group
  - Lack of flexibility and over-bureaucratic scrutiny [none of our respondents have used them]

The unequal experience of caring

- Overall, those who fared better were wealthier, healthier, with strong networks of social and community support, and those who had key points of contact of individuals who they knew well and could help them navigate what they needed at points of need

Legal implications?

Some legal implications of these findings

- Without easements, were the actions described above that Local Authorities took across the board likely to have resulted in breaches of statutory duty under the Care Act?
    - Ambiguity as to what Local Authorities are actually required to do under the Care Act
    - Although much guidance, varying interpretations as to what the law is – very few cases, leads to widely diverging views

- If the actions taken by Local Authorities were in full compliance with the Care Act, is this desirable as a matter of social policy? Are those statutory duties robust enough to protect carers and people being supported?
- How should we interpret statutory duties in the face of people declining to have carers in-house when those carers potentially carried a risk of death to the recipients?
    - What is a reasonable offer of care and support in these circumstances?

Moral hazards and the law

- Political and legal focus was on preventing easements (and largely succeeded), rather than on challenging Local Authorities that had not enacted easements for reduced service provision.
  - What were the potential moral hazards of challenging reduced service provision?
  - What might have been the outcome for individuals of challenging reduced service provision?

Next steps

Next steps

- Survey in the field; survey analysis
- Publications (including legal analysis)
- Briefing notes
- Final report & dissemination

Further socio-legal research

- What do people do when they perceive quality of home care to be deficient?
- How useful are the mechanisms for challenging provision under the Care Act as a way of ensuring or maintaining quality of home care?
- What other levers exist to govern quality of home care?

Thank You
Q&A