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

DHSC presentation: 10 November 2021 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.

What are '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 Objectives

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

Secondary Objectives

- Document impact of Care Act easements and reinstatement of statutory duties
- Compare and contrast experiences in Local Authority areas with easements and those without
- Understand challenges and dilemmas for those with safeguarding responsibilities
- Understand and document urgent challenges for carers and local authorities

Three 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)

Carer Advisory Group





Where we are now (half-way)

- Undertaken 22 carer interviews (40:60 easement/non-easement) [May to November 2021]
- Undertaken 25 local authority PSW/SL interviews across 19 local authorities (6 easement/13 noneasement) [May to November 2021]
- Survey developed in collaboration with advisory group and stakeholders. Awaiting ethical approval
- Developed node structure for qualitative analysis critical realist perspective; Spradley's Developmental Research Sequence Methods of analysis
- **Today**: interim findings from preliminary analysis of local authority and carer interviews
 - (to note: our respondents talk about "enacting easements" and so this is the language we have adopted in this presentation)





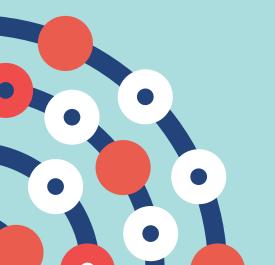
Outline

- What happened to assessments and services
- Decisions to enact easements
- Care versus health
- Socio-legal questions arising
- Next steps & further research





What happened to assessment and services?



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 abuse might be taking place
 - Circumstances of phone call 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





So we took the decision to just do Level 3 and what that meant for us, we were going to divert – the main thing we were going to do was divert our review team resource, from reviews, annual reviews, to front line delivery, and that was one of the ways that we got through those waiting lists as I described. So we felt it was much more important to make sure people got the care and support they needed now, than checking the year on whether it was still okay. And I know from back in the day, when I did it, you know, your assessment process started at the garden gate. You know, you'd see what the outside of the house was like. It would tell you a bit about the person's mobility, their motivation, all of those things you don't get on the phone.

And I think it's important to say if you are doing digital assessments you're not as a practitioner able to sit in somebody's home environment and understand what's happening in that environment, what's it like, what the levels of care are. What the levels of appropriateness are or self-neglect are, 'cos actually it's like me and you, Phil, isn't it? You're sat there, I'm sat here. I can't see your house, so you could have cleared that space and made it look lovely, and everywhere else could have been an absolute hoarding paradise.



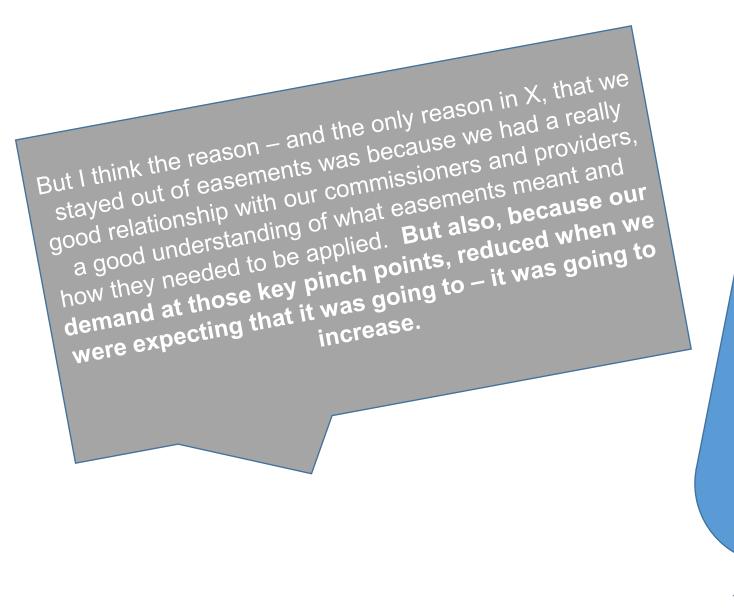


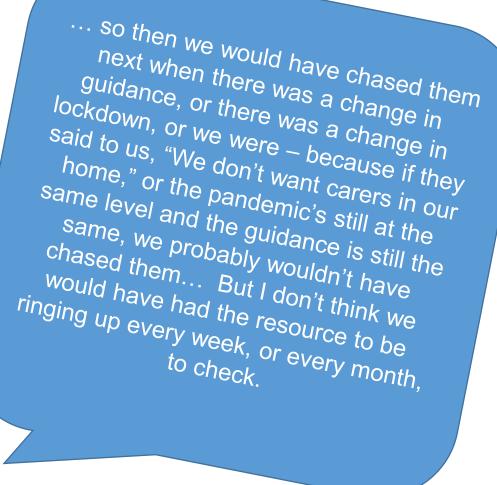
In-home care stopped in many cases

- Often, but not always, at the request of the couple
 - Real and present dangers of allowing carers in to put them at risk (being communicated daily by government)
 - Carers often young, moving from home to home, different carers every day, no or variable PPE, potential asymptomatic spread
 - Very high risk of serious illness and death to older people, especially those living with a number of conditions including/in addition to dementia [pretty much all of this client group]
 - Also, perception by recipients that very poor quality care being received (so it might as well stop)
 - Without recipients declining to allow carers/other help in, some local authorities would have been compelled to enact easements
- Interaction with furlough important (unintended) interaction between furlough system releasing family members for care, and local authorities unable to provide care
 - Without furlough some local authorities would have been compelled to enact easements
- 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
 - While some carers appreciated it, other carers did not find calls helpful where no further assistance
 was available especially when from a person who didn't know them









NIHR Policy Research Unit Older People and Frailty



Day Centres & Respite Care

- Community initiatives centres and offices closed but volunteering temporarily up
- 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





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 needed a break from that and obviously we realised it was the infection, it wanted treating and obviously things settled down and 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





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.





Referrals down/an invisible group

- Not seeing GPs (prior to the pandemic a significant route for referrals), memory clinics [dementia diagnoses down], safeguarding referrals down
- Day Centres and Third Sector largely closed
 - Key in noticing people needed help and referring
- For older (70+) carers, often only come to the attention of the local authority via crisis admissions to hospital
- Local authority have great difficulty in identifying this at-risk group if they are not already in touch
 - GP flags very poor or non-existent
- The "shadow" pandemic, shielding, isolated safeguarding referrals dropped during the pandemic but have gone up substantially now





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
 - Carers on our advisory group report lack of flexibility and over-bureaucratic scrutiny [none of our respondents have used them]



Consequences

- Consequences of stopping and changing all these services not known – no investigations/reviews of impact – resources stretched
- For carers: a "minefield" of trying to navigate help
 - Easier if there was a named person and single point of contact who knows the whole system, they already knew well, who they could call on, and would not be signposted on any further
 - Those with greater wealth, income, social assets, family close by who continued to help, community support from neighbours, managed better
 - Pre-emptive concerns about care quality ('knowing' it would be bad so wouldn't consider engaging with the local authority)





Decisions to enact easements



Same circumstances, different decisions

- Circumstances and responses across the country in social care were similar but legal interpretations as to the Care Act consequences differed
- Led to different decisions being made as to whether easements needed to be enacted e.g. for:
 - Lack of choice in residential care/respite
 - Reducing and streamlining assessments
 - Changes in communications about assessments
 - Closure of day services
 - Diverting resources from reviews to front-line delivery
 - Fear about staffing levels and potential ability to fulfil statutory duties
- These outcomes were being experienced around the country: in some LAs but not others this led to easements being enacted
- Substantial ambiguity around the law and its interpretation





Government information and regional networks

- Government information seen as needed and sometimes helpful but also overwhelming, constantly changing, confusing and inconsistent; information coming from multiple sources, particularly in the early stages
- Ethical framework: right questions and issues (helpful) but little guidance as to what easements could or should look like on the ground
- Easement legislation itself necessitated tight governance, scrutiny and clear decision making – regardless of whether easements had been enacted or indeed had ended, which many saw as beneficial
- Professional regional networks (PSW/ADASS) become highly significant places of information sharing and learning
- Led to regional clustering in decision making around easements





The political and discursive storm

- Considerable backlash against easements from lobby groups, politicians, the media, the public, FOI requests, legal threats
 - The politics influenced at least one of our respondent LAs from enacting easements
- Those who enacted believed they were being more open, transparent, honest, democratic – what was happening not being hidden, enabling scrutiny of triage and prioritisation
 - Believed what they were doing was right, felt vilified at the attacks
 - Were surprised at the attacks; surprised that others were making different decisions
 - Retreated quite quickly; while one LA said they would enact again if needed, another said "never again"
- The narrative was very negative stigmatising, harmful, demoralising, unfair







Care versus health



Care versus Health

- Marked contrast with NHS the law permitted triage, rationing, operational prioritisation without enacting easements and thus escaping the political, legal and media barrage
- Much resentment about the lack of support and lack of appreciation given to the social care sector (then and ongoing)
- Social care viewed as the "poor relation" to health; vital role not recognised
- Situation now for social care perceived as much more serious than at any stage in the pandemic: emotional burden, burnout, staff shortages, low pay, lack of funds, lack of political and social recognition
 - Exit of experienced workforce, inability to recruit and retain staff
 - Short term funding not helpful for long term stability, commissioning things that will last, and solving recurring problems
 - Deep concern about the current situation and the future





They've had sixteen months reflect on what is a really, really demanding emotionally, psychologically, physically demanding job. And I think a few people who we've known for a very long time, dedicated, committed support workers, social workers, wellbeing assessors, that are saying, "I can't do this anymore. I can't do it anymore. I'm done."

So, we've got to do something very – if you can do anything from the DoH or government, we have got to do something very quickly to show people that we appreciate them. We are going to invest in them, you know, we are going to support in their learning development and we do want them to stay with us.

NIHR Policy Research Unit Older People and Frailty

People are leaving in droves. We tried recruiting to

the short-term posts because we had the short-term

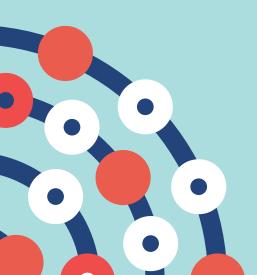
money, but we can't even recruit to permanent posts

because nobody wants to do social work any more.





Socio-legal questions arising



Socio-Legal Questions (1)

- 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?
- Why were different Local Authorities being given diverse and inconsistent legal advice on their statutory duties?
- Does the Care Act/Coronavirus Act enable Local Authorities to institute across-the-board responses?
- 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?





Socio-Legal Questions (2)

- 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?
- 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?





Socio-Legal Questions (3)

- How useful are the mechanisms for challenging provision under the Care Act in the pandemic?
- Why are so few cases brought under the Care Act? (some complaints are emerging via the LGSC Ombudsman)
 - Balance of power
 - Inequalities
 - Legal aid for the poorest but stakes are high (costs, relationship with local authority)
- 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







Next steps

Next steps

- Briefing note from this presentation
- Deeper analysis of local authority transcripts
- Continue with carer interviews and analysis of interview transcripts
- Survey in the field (Nov/Dec); survey analysis
- Final report & dissemination
- Journal publications
- Ad hoc briefing notes on specific issues



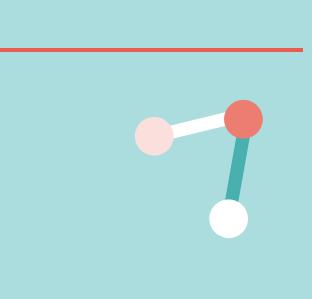


Further research?

- Understanding care deficits for older people from multiple perspectives:
 - how thresholds of "reasonable provision" under the Care Act are interpreted, and how these relate to needs and expectations from older carers
 - how quality of domiciliary care is understood by funders and recipients
 - the meaning and experience of respite care
 - how self-funders and local authorities respectively conceptualise and meet needs
 - Implications for care cap debates
- Moral distress and emotional dissonance experienced by the social care workforce in and following the pandemic – implications for workforce management and practice
 - meeting legal obligations in conflict with doing good social work



Thank You Q&A



Spradley's Developmental Research Sequence Method

- 1. Strict inclusion
- 2. Spatial
- 3. Cause-effect
- 4. Rationale
- 5. Location for action
- 6. Function

7.

8.

9.

- Means-end
 - Sequence
 - Attribution

X is a kind of Y X is a place in Y, X is a part of Y X is a result of Y, X is a cause of Y X is a reason for doing Y X is a place for doing Y X is used for Y X is used for Y X is a way to do Y X is a step (stage) in Y X is an attribute (characteristic) of Y