Carer Harm: Challenges for Policy & Practice
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Terminological & conceptual issues

- Carer harm challenges a number of dominant narratives that underpin policy & practice relating to carers & their relatives:
  - There is a widely held perception that people with care & support needs are 'vulnerable', lack agency and/or the ability to exercise (any) power or control
  - This view intersects with the constraining binary discourse about who can *legitimately* be regarded as a 'victim' or a 'perpetrator' of abuse (Isham et al., 2020)
  - It unsettles the persistent framing of family caring as 'virtuous & natural' & care relationships as positive (Manthorpe and Iiffe, 2016)
- The organising focus of *intentionality* is also an issue: it can obscure the complexity of caring & act as a barrier to help-seeking:
  - Most carers are reluctant to use the term *carer harm* or to describe the person with care and support needs as *abusive* especially if they view it as unintentional eg arising from a health condition such as dementia
  - *But….* this does not change the fact that the carer is harmed (Donnelly et al., 2025)
  - *'It's about recognising that a lot of people are suffering as I did. You can't… be critical of someone who is ill. It's not the illness but it's the effect it has…we need a word to describe the effect on the caregiver, rather than the service user being an 'abuser'. That's what I would like to try and find' -*'Mary', spouse carer

Practice Related Issues

- The system does not know what to 'do' about carer harm; struggles to respond

- Carers are already ill supported (exploited?):

  - In the UK evidence of increasing marginalisation of carer rights to assessment & support despite *Care Act (2014)* - worse in context of austerity & local authority retrenchment

  - Even greater drive to treat carers as 'unpaid members of the care workforce' or a free resource: the care system *explicitly* depends on carers input

- Lack of a 'safety net' for carers; delayed, short term & disrupted interactions with social workers - limited opportunity to look below the surface or engage with behaviour(s) that concern the carer and/or are harmful

- Challenges are often faced by social workers - and other professionals - when care and harm intersect, & an adult with care & support needs is the alleged perpetrator:

  - Barriers to recognition include: reluctance to engage with the issues, partly driven by dependency on carers; lack of professional curiosity & time; excessive workloads; challenges inherent in multiagency working & information sharing (Doyle et al., 2023)

  - Practitioners often collude with the model of 'more training' for carers or 'behavioural interventions' for the person being looked after

Practitioner Perspectives

'I think that looking after carers, it is the biggest thing that we don't do well… by a long chalk. I think that we are good at a lot of things… but I think that our thinking is limited. I wouldn't even ask my manager for certain things (for carers) because….well… it's almost unfair to ask her because you know that she will feel rotten by having to say no, we can't do that'

Andy, social worker

'There is no formal guidance or accepted procedure for what we do to help keep carers safe. And I have had this concept in my mind before, when I have been on duty. And I have said, bloody hell, this person could be dead tomorrow but there is nothing there, there is no safety net'

Jan, social worker

Lessons from, and for, practice…

- Evidence from emerging work that focuses on the lived experiences of carers who have been harmed suggests that:
  - Practitioners should adopt trauma informed approaches
  - Use language that 'fits' with the carers' own language
  - Allow carers to 'tell their own stories' re the challenges they are facing & how they would like to be supported: this may include withdrawing from the caring role (Holt & Burchill, 2022)
  - Also 'read across' & partnership working with carers agencies and MDT colleagues
- Social workers can play a crucial role in attending to epistemic issues by sensitively and proactively exploring what harm might look *and* feel like to carers: being open to testimony (Fricker, 2007)
  - Strong case for ensuring that carer assessments are not just about 'keeping carers caring' but that they - sensitively - address issues of harm, risk & protection (Milne & Larkin, 2023)
  - Named social worker role for care dyad/family: engage proactively with carer & cared for person + focus on acknowledging harmful behaviours & reducing risks

What helps carers?

- *Advocacy*

- *Routine and proactive assessment* of family carers' support needs, coping capacity & the impact of caregiving on their physical and mental health

- *Collaboration & utilisation* of community-based data & expertise such as Gardaí (the police)

- *Education and training*: Understanding by practitioners of the condition(s) of the person with care & support needs

- *Establishing peer support groups for carers* was seen as hugely beneficial in providing a space to share concerns or experiences of carer harm

- The provision of *family therapy* focusing on the whole family unit allows each family member to voice their worries, concerns and wishes

Policy Issues: what may help…

- A range of intersecting enforceable legal rights would help to ensure that carers were better protected:

  - A *statutory entitlement* to services for *both* the carer and the person with care & support needs (only have this for an assessment of need currently)

  - Legal *right* for carers to be protected from harm & to live without fear of abuse

  - At present there is *no meaningful limit* on demands on carers including what they are expected to tolerate in terms of abuse

- Competing rights 'carer vs user': How are these rights to be meaningfully operationalised & by whom?

- Family care is currently a 'privatised risk' - families bear all of the costs & responsibilities for care:

  - Case for treating care as a *social risk* ie. a risk that is shared with wider society & the state: offer social protections to carers such as care services, welfare payments, rights to remain in work (Morgan, 2018)

  - Promote *social justice* for carers: advance an understanding of care as an integral part of all human relationships & a product of normative interdependence & reciprocity

  - Thinking about carer harm as a form of *social harm:* a harm that is embedded in relationships and is rooted in a family/social context

Mairead's Story

'There was an incident where a carer was hurt so, so it was just the two carers in the room at the time so, you know, obviously we weren't there to see what happened... A carer got injured... and then the next day at four o'clock in the afternoon, I got a phone call from the Manager of Older Person Services in the area, advising me that care had been withdrawn with immediate effect, from my Dad. So, she advised that he was, that there was a physical assault within the home, that the man needed a psychiatric assessment and it wasn't safe for her employees to be coming into the home and that we could expect a call from the Gardaí.'
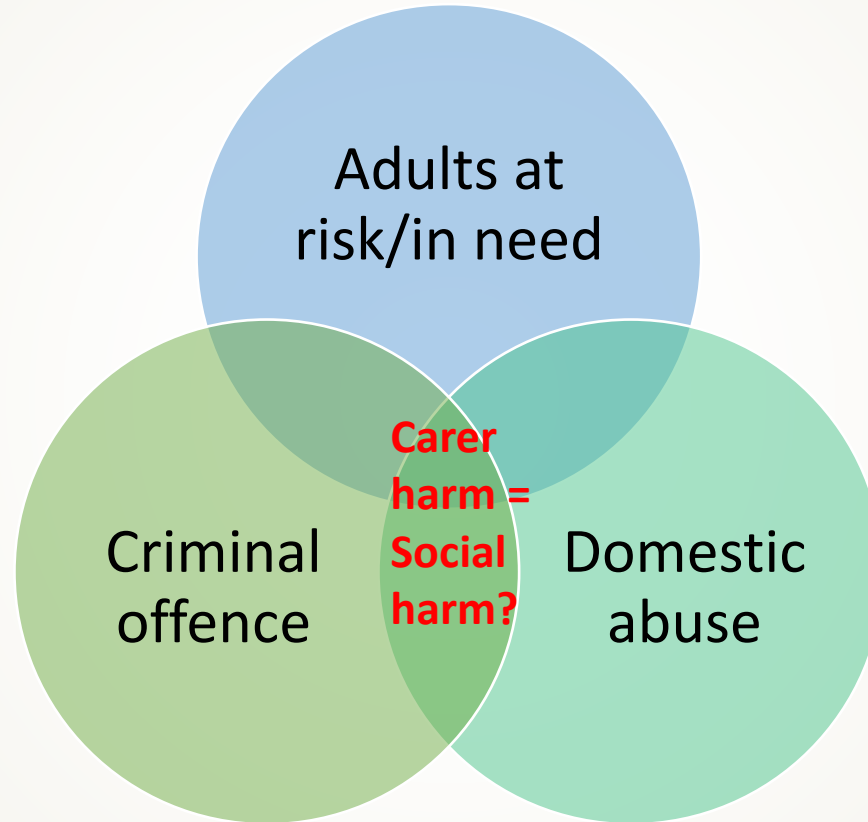
(Mairead, Dementia Family Carer)

Key considerations

- The need for family caring is growing (as noted) alongside a reduction in the 'supply' of family carers: demands on carers are likely to increase further in the future

- Carer harm is also likely to increase:

  - '…. abuse of unpaid family carers can flourish where the demand for care is great & where there are complexities in relation to the needs of the cared for person' (Anka & Penhale, 2024, p8)

  - May be exacerbated in contexts where the cared for person lacks understanding of the harm caused by the abuse

  - Where there are few services and/or they are tightly rationed

- If carers are being harmed, the welfare system needs to develop specific & effective ways to protect them:

  - Current responses do not appear to be providing protection: in the UK the care system struggles with the issue(s)

- Wider recognition of carers at risk of harm helps to make the issue visible in policy, the welfare system & practice

- Carer harm is under-researched - more empirical work is needed, also conceptual thinking & theory building
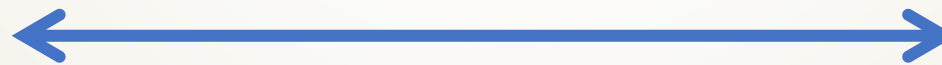
Towards a conceptual model of carer harm….

Welfare Paradigm

Social Justice Paradigm

Adults at risk/in need

Carer harm = Social harm?

Criminal offence

Domestic abuse

Room for a Human Rights Framework?

Intentional ⟵⟶ Unintentional

Who is responsible for responding to carer harm?

Key References

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