





# Critical Questions for Consideration

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- ▶ Is Carer Harm recognised as an issue in your jurisdiction/work?
- ▶ What happens with these types of cases/how are they currently dealt with?
- ▶ Where do responses/policy currently sit in relation to this issue?
- ▶ Is it viewed as intentional or unintentional harm & what difference does that make to responses?
- ▶ Practitioners' confidence working with affected families and/or what are the key challenges experienced by social workers in these situations?



# What is a Family Carer?

- ▶ 'A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support' (Carers Trust, 2024).
- ▶ In Europe, 80% of all long-term care is provided by family carers i.e. people who provide unpaid care to a relative (usually) with a chronic illness, disability, or other long-term health or care need.
- ▶ There is a growing demand for family care too.
- ▶ Key drivers include the ageing profile of the population(s) alongside growing numbers of adults of working age with long-term health conditions; the impact of neoliberalism on service provision and reduced use of institutional care are also factors (Milne and Larkin, 2023).



# Demographics of Carers

- Responsibility for providing care has shifted almost completely away from formal services onto families (Fraser, 2016).
- In the UK, 6.5 million people - 10.4% of the adult population - have some kind of caring responsibility (EIGH, 2022; Milne and Larkin, 2023).
- In Ireland 85.9% of *all* care is provided by family carers (Care Alliance, 2018).
- 53% increase in the number of family carers in Ireland from 195,263 people in 2016 to 299,128 in 2022; a larger proportion of carers are female (Census, 2022).
- It has been estimated that family carers save the Irish state €22 billion per Annum (FCI, 2022).



# Complexity of Caregiving

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- ▶ Increased risk of impaired physical and mental health, becoming socially isolated, insecure employment and poverty (Carmichael and Ercolani 2016).
- ▶ Significant challenges in accessing any support from services (FCI, 2022).
- ▶ Challenges of caring may result in a state of cumulative and prolonged stress, commonly referred to as “caregiver burden” (Isham et al.,2017)/Bidirectional Harm
- ▶ Risks of carers intentionally or unintentionally lashing out or abusing the person they are supporting is heightened in these circumstances (Momtaz, Hamid, & Ibrahim, 2013).



# Understanding harm and/or abuse in caring contexts

- Social, emotional and psychological consequences of harm in caring contexts emerging from small but growing literature, in different countries and caring contexts (Miles and Condry, 2015; Spencer et al, 2017; Donnelley and O'Brien, 2023).
- England and Wales. Emerging evidence of the intersections between long-term caring patterns, co-existing adult 'vulnerabilities' and serious and sometimes lethal violence in domestic homicide reviews (Benbow et al, 2019; Bracewell et al, 2022) and mental health homicide reviews.
- England. Evidence of increasing marginalization of carer rights to assessment and support despite Care Act (2014) in contexts of austerity and LA retrenchment.
- Increasing expectations and lack of a 'safety net' for carers; delayed and disrupted interactions with social workers.
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# 'Dangerous Care'

(Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019).

Key findings from the current report, *Paying the Price: The Hidden Impacts of Caring*.

**44%**

of carers surveyed regularly deal with abusive behaviour

**70%**

of carers experiencing abuse as part of their caring role said their loved one did not have access to suitable respite

**76%**

of care recipients did not receive any home support hours

**74%**

of care recipients requiring 100+ hours of care per week had no access to home support hours

**49%**

of carers said that no supports and services were available

**79%**

of carers supporting children with care needs found it difficult to make ends meet

**25%**

of carers could not access supports and services due to distance and/or transport issues





# What is Carer Harm?

- ▶ 'Carer harm' is when carers experience violence or become subject to controlling or coercive behaviour, either on an incidental or systematic basis, resulting in physical, psychological and/or sexual harm (Isham et al.2020, p.2).
- ▶ Clear evidence of the significant, long-term negative impact on the health of those who experience abuse (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019).
- ▶ Challenges are often faced by social workers and other professionals when care and harm intersect, and a service user/child is the alleged perpetrator of harm against their family carer.
- ▶ There have been calls for all stakeholders to work more proactively with families where care and harm intersect (Isham et al.2020; Donnelly and O'Brien, 2023).





# What we know...

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- Elder abuse can be a continuation of harm that began in earlier years

## **Harm and abuse in later years linked to:**

- Cumulative impact of advantage/disadvantage over the life course
- Health inequalities widen for age cohorts over time
- Increasing care needs are associated with the risk of abuse

## **Inadequate service responses can:**

- Perpetuate and aggravate harmful and abusive situations
- Create conditions where harm and abuse can emerge

## **Impact of COVID19 and continued 'Austerity' policies**

- Reduced support for disabled and older people, and carers.
- Increased adult safeguarding referrals
- No data on the number of carers who are exposed to harm by the cared for person or the nature of that harm





# 'Hiding' Carer Harm

(Donnelly and O'Brien, 2023)

*'This is not willful abuse like it's abuse but within the context of that person's autism and responsive behaviours.'*  
(Autism Focus Group Participant).

*'You know when we think of carer harm, again I struggle with the language... and I was thinking in my own head when you were talking, what other language could you use. I don't know.'*  
(Dementia Professional Focus Group Participant)

*'Some people I find would never describe it as carer harm, they would never use the word like I feel...'*  
(FCI Focus Group Participant)



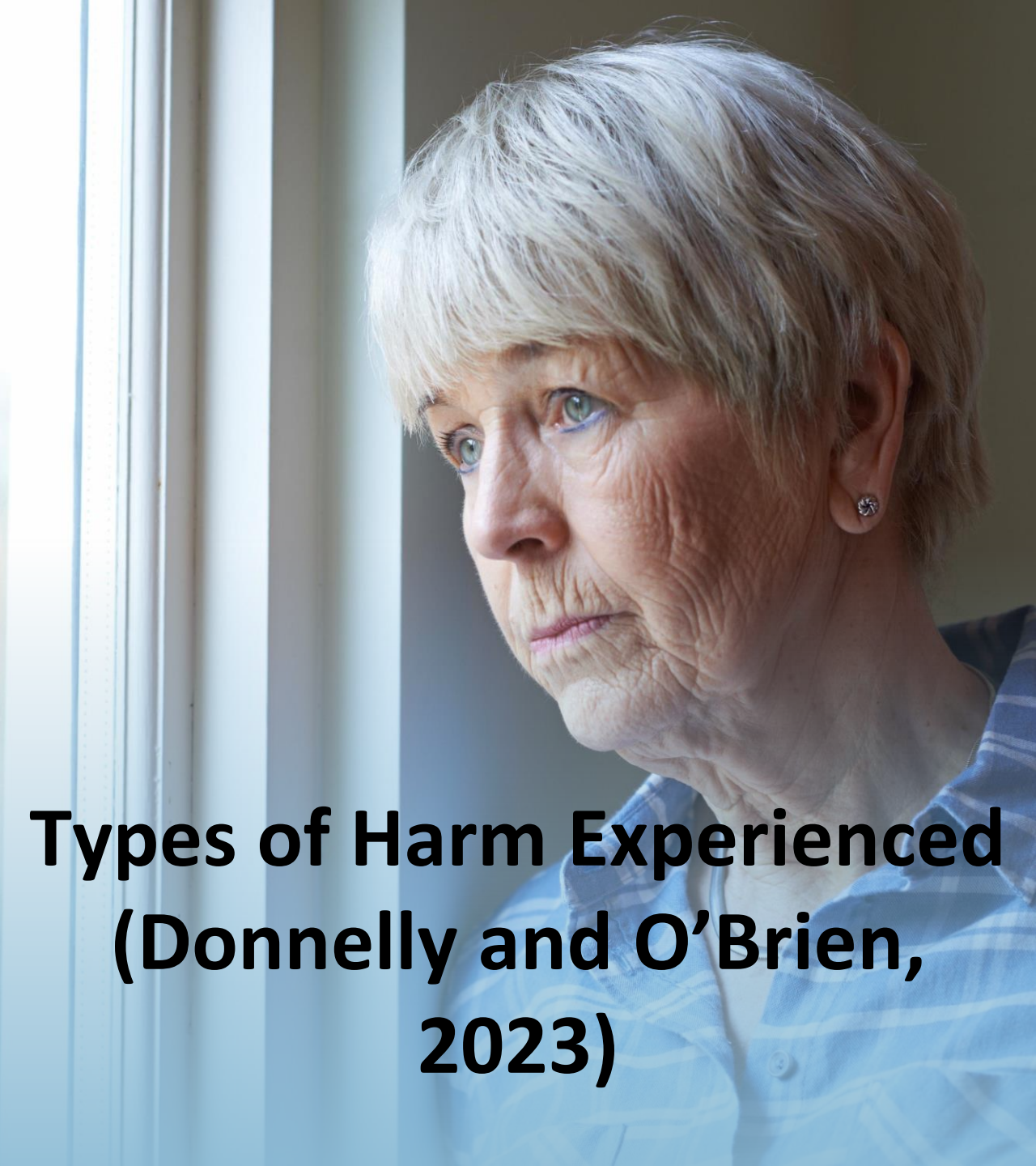
# Isham (2020;2021)

*“I think that, that that’s, for me... its about recognising that a lot of people are suffering as I did. You can’t, you can’t... can you be critical of someone who is ill? It’s not the illness but it is the effect that it has on you and I think that we need a word to describe the effect on the person, on the caregiver, rather than then the service user being an ‘abuser’. That’s what I would like to try and find”.*

(Mary, caring for her husband)







# Types of Harm Experienced (Donnelly and O'Brien, 2023)

Wide range of types of harm reported; shouting, screaming, damage and destruction of personal possessions or the family home and significant levels of physical violence as well as knock-on emotional and psychological distress.

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Impact on their own health and wellbeing as well as the impact on siblings (autism carers) and other family members (dementia carers).

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Professionals described the type of harm experienced by family carers: physical aggression/assaults emotional toll, impact on the family carers' mental health.

# Carer Harm

## Stigma, Shame and Guilt

(Donnelly and O'Brien, 2023)



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*'I find that when I have carers wanting to talk to me and share their experience, they are very apologetic, you know, please don't judge me...So certainly, it's almost like guilt, so much guilt you know, I should not be disloyal to my loved one by discussing this.'*

(Dementia Focus Group Participant)

*'That sense of guilt, failure and you know all those pieces, so I think the emotional toll is probably the more difficult than the physical toll that's happening when we come to carer harm. That physiological or psychological fear to go out of the home, fear of shame, all those pieces really resonate'*

(FCI Focus Group Participant)



## *Isham (2020;2021)*

*“I used to feel shame and embarrassment about going out after there had been lots of shouting and violence. I was worried about what the neighbours would think. I stayed inside; I wanted to stay hidden. You take on the shame of your loved one’s behaviour because you know that people don’t understand why they are acting in a difficult or upsetting way. You also worry that people blame you and hold you responsible. There are so many layers to how this affects your life”.*

Rose, caring for her husband



*“He (dad) started to walk around with a knife in his pocket. And I’m telling them, the social workers, ‘no, this is not going to work! It’s not going to work for someone to be living here with him, it’s not safe!’ And then they (social workers) decided to come and they said about putting him in the respite for two weeks and I had to say, ‘no, no, no, that is not enough, two weeks is not enough!’”*

Dorris, previously caring for her father

*“I feel disloyal talking about this.... That’s the feeling that you have to understand. That’s the feeling that inhibits you, because you feel guilty”.*

Sarah, caring for her husband

*'So, some nights she's screaming outside my door, she's confused, and she gets agitated in the middle of night so some nights I could be up all night with her trying to settle her and get her back to bed. And obviously, she comes up screaming that wakes the kids up so some nights are awful...it's like having another child in the house'*

(Jennifer, Dementia Carer).

## Jennifer's Story

(Donnelly and O'Brien,  
2023)

# Dangerous Care and Systems That Harm

- Harm caused or exacerbated due to lack of services and how Healthcare Professionals engage with family carers.
- Double standards
- Professional helplessness and frustration: inability to respond (Donnelly and O'Brien, 2023).

*“ Dangerous Care refers to harm that might occur between individuals, but also how welfare policy and service delivery can create and aggravate the stresses within such relationships and responses to these.”*

(Sherwood-Johnson et al. 2023, p.5)

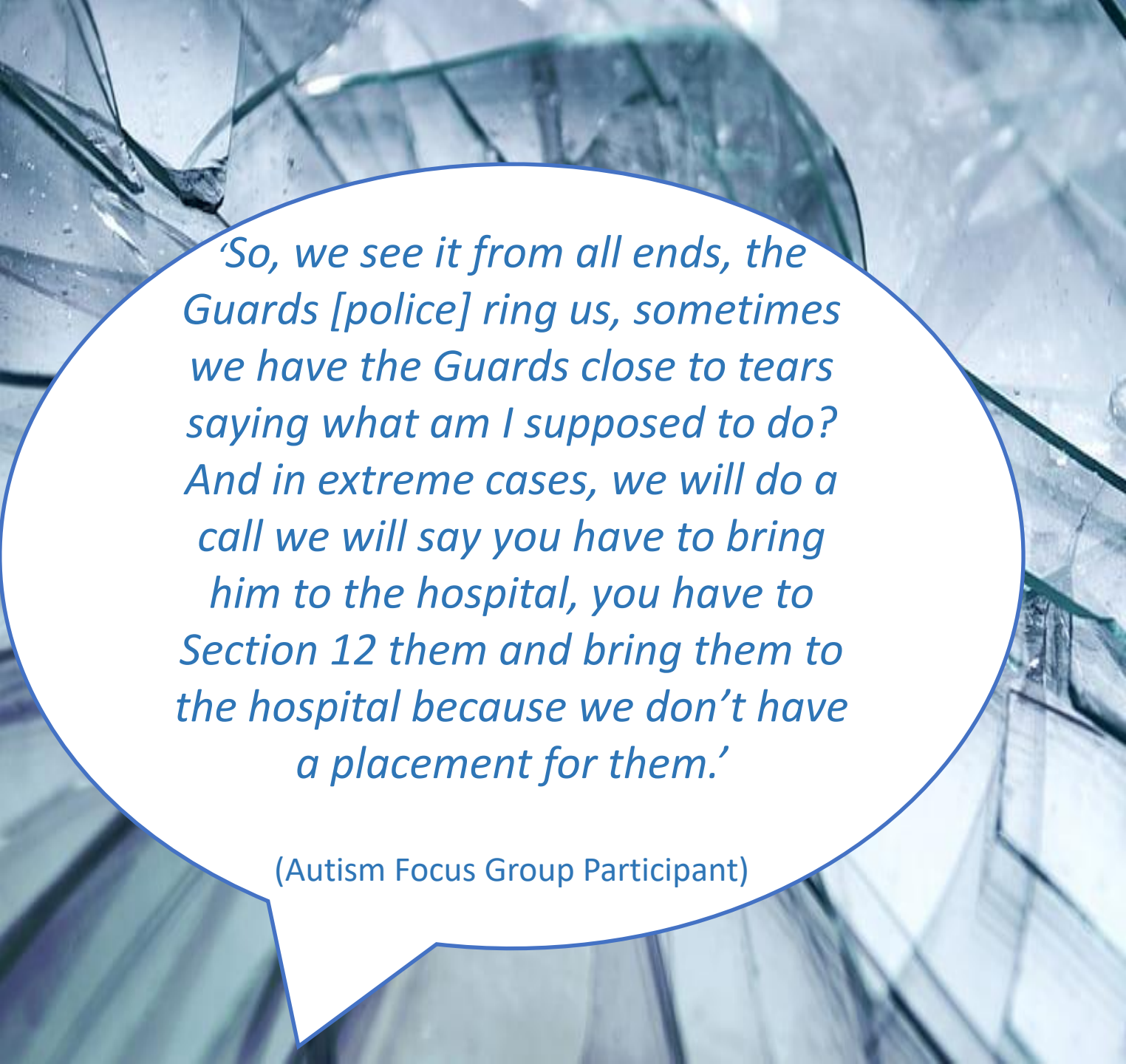




*The Disability Officer was in the HSE, she is charged with getting families like ours something if it's just like gone to complete rock bottom and the family can't cope. And we were told as well, which was not helpful,  
'You are not the worst case. There's a lot worse out there than you'.*

(Paula and Sean, Autism Carers)

Systems that  
Harm



*'So, we see it from all ends, the Guards [police] ring us, sometimes we have the Guards close to tears saying what am I supposed to do? And in extreme cases, we will do a call we will say you have to bring him to the hospital, you have to Section 12 them and bring them to the hospital because we don't have a placement for them.'*

(Autism Focus Group Participant)

No way to respond

(Donnelly and O'Brien, 2023)



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## Are you experiencing Carer Harm?

If you are a family carer, ask yourself:  
Does the person I care for behave in a way that causes me physical injury, emotional pain, or other kind of harm?  
In my engagement with professionals and organisations, is my coping capacity and need for support recognized and responded to?

This leaflet may be useful to any family carer experiencing carer harm

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## Carer Harm - Best Practice Considerations for Professionals

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## Understanding Carer Harm

Dr Sarah Donnelly and Dr Marita O'Brien,  
School of Social Policy, Social Work and Social Justice, UCD.

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# Understanding Carer Harm Study Outputs

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This leaflet may be useful to carers of autistic adults or children

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# Exploring unintentional ‘carer harm’—Insights from family carers and professionals: An Irish case study

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