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IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

Understanding Carer Harm

IASW Social Workers in
Disability Conference

Wednesday 11th October 2023



Carers and Domestic Abuse

(Warburton Wynn, 2022)

- Abuse may have been ongoing for a long time or may be as a result of illness
- Carers can be isolated – restrictions on time away from the home or visits from friends/family
- Feeling controlled into providing care, feeling trapped
- Losing their own identity
- Worried about consequences if they ask for help
- Close proximity of personal care – physical violence, sexual abuse
- Emotional abuse and control – feeling they can't leave
- Isolation



'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).
- While the risk of deterioration in carers' health and wellbeing as a result of caring has been well documented, there is also 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).
- Little is known about the harm experienced by carers at the hands of the person for whom they provide care to
- 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).

Recommendations from 2019 Report

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

The impact of physical and verbal abuse on family carers remains hidden and under-researched.

Further research and public discussion on this hitherto hidden aspect of the caring experience is key to recognising carers as victims of abuse and developing effective interventions to allow them to care safely.

Research Design

Understanding Carer Harm

Research questions: What are the perceptions and experiences of family carers of carer harm by care recipients and how can they be better supported by professionals?

Work package 1: Secondary Data Analysis (SDA)

SDA of qualitative data set from 'Paying the Price: The Hidden Impacts of Caring Report' (FCI, 2019).

Work package 2

Narrative interviews

- N= 5 FCI carers of children/adults with autism
- N=4 FCI carers of PLWD who have experienced carer harm.
- 1 x interview with Autism Education providers and FCI Senior Manager.

Focus Groups

- 1 x FCI Case Support Managers
- 1 x Autism Professionals
- 1 x Dementia Professionals

Evidence

Understanding carer harm from perspective of key stakeholders (existing practice, cultural norms, social influences, family carer preferences, professional behaviours, what helps)

Work package 3 World Café Co-Design workshops

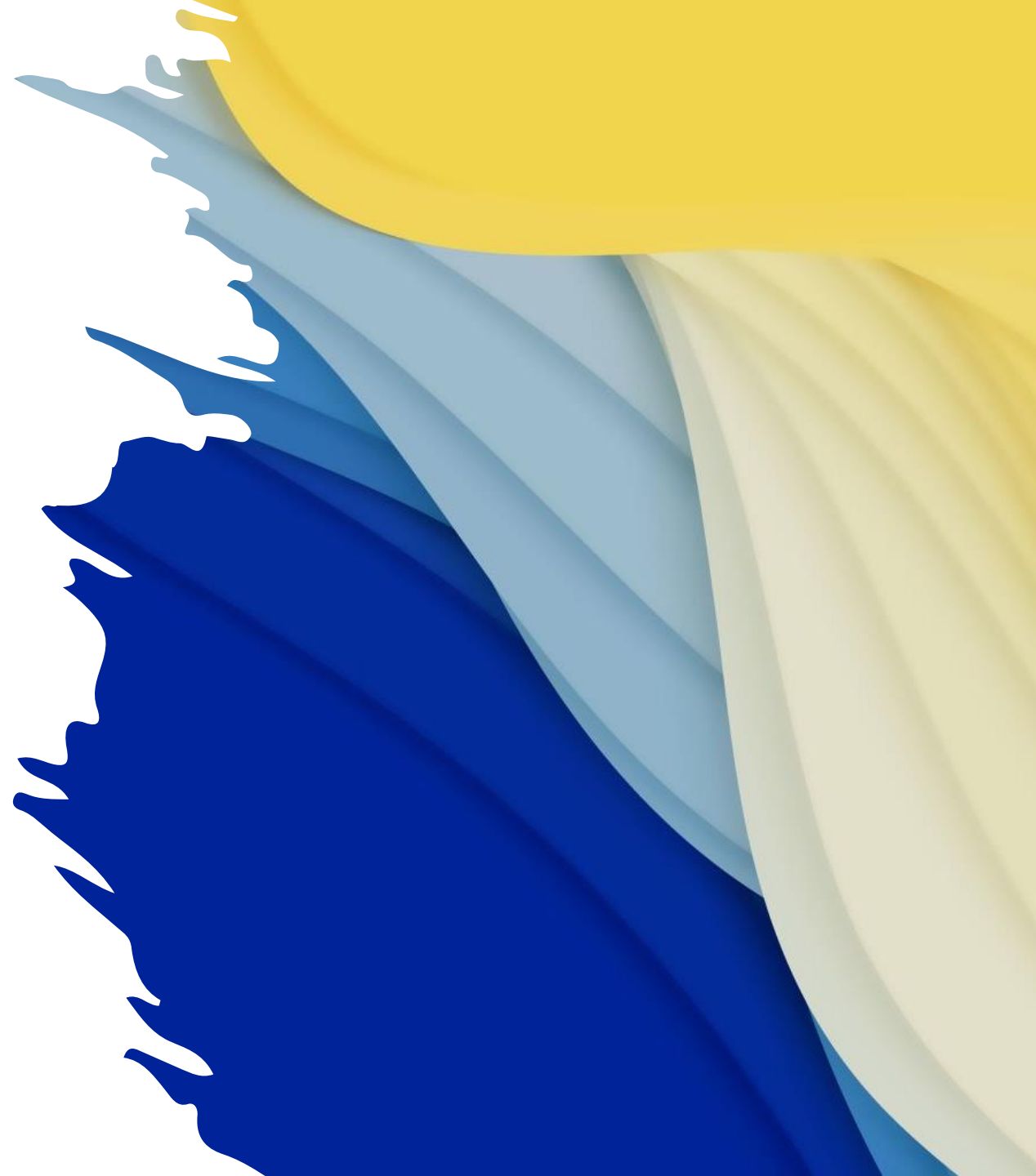
Intervention development

- User co-design participatory approach
- Content informed by evidence gathered in WP 1 and 2.
- WP 3: Resources for Family Carers and Practice Guide for Professionals

**Output 1
Information and Support Resources for Family Carers**

**Output 2
Best Practice Considerations for Professionals**

Narrative Interview and Focus Group Findings



A purposeful sampling approach was employed. Narrative interviews were carried out with five family carers of autistic children/adults and four family carers of PLWD. Two educators and a FCI Senior Manager also participated in interviews.



In all fourteen people participated in the three focus groups, including FCI Support Managers, a FCI Senior Manager, social workers from Tusla, Child and Adolescent Mental Health Services (CAMHS), Safeguarding and Protection Teams, Disability service provider, Medical, Dementia Nurse Specialist, Dementia Adviser, Advanced Nurse Practitioner and an Occupational Therapist.



Each World Café session (autism-specific and dementia-specific) had twelve participants which included family carers, social workers and representatives from NGO and advocacy organisations.



Study Participants

Table 1: Autism Interview Participants

Autism Family Carer	Relationship to Care Recipient
Katrina	Mother to 2 autistic sons (adults)
Paula and Sean	Parents of 12-year-old autistic son
Valerie	Mother to 12-year-old autistic son
Noleen	Mother to a 12-year-old autistic daughter
Lana	Mother to 17-year-old autistic son

Table 2: Dementia Interview Participants

Dementia Carer	Relationship to Care recipient
Patrice	Wife
Mairead	Daughter
Jennifer	Daughter
Oonagh	Daughter

Narrative Interview and Focus Groups Themes

Narrative Interview and Focus Groups Themes

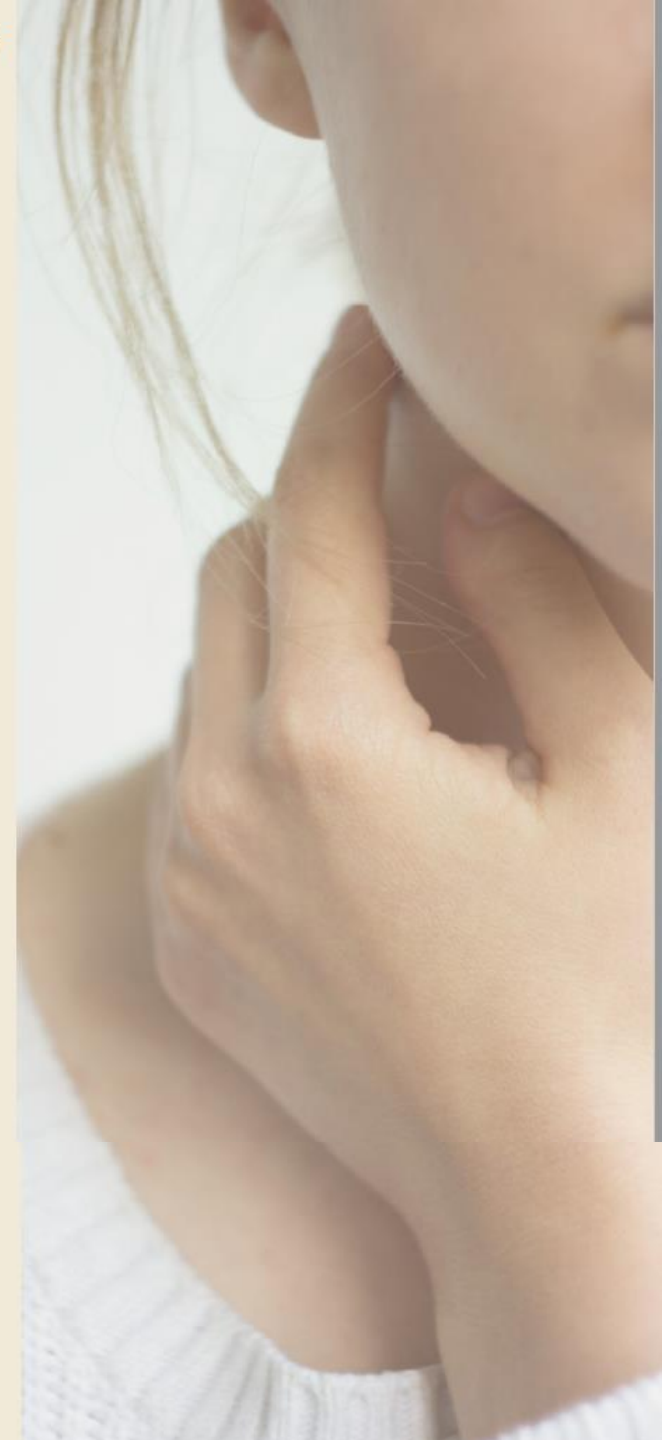
1. Understanding Carer Harm

- Carer Harm- how to define it?
- Stigma, Shame and Guilt
- Types of Carer Harm
- Expectations, Responses and Systems that Harm

2. Protecting Family Carers from Carer Harm

- Diagnosis: a critical juncture
- Early Intervention
- Transitions and Changing Care Needs
- Navigating a fragmented and complex health and social care system
- Professional helplessness and inability to respond

3. What Helps?





1. Understanding Carer Harm

Difficulties with defining and understanding the terminology 'carer harm'- participants reported how the term is not instantly recognisable, nor is it well understood or regularly used in the everyday language of professionals or by family carers.

Defining Carer Harm



'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)

'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).

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

Stigma Shame and Guilt



- ❖ Stigma and shame were identified as barriers for family carers in disclosing their experiences of carer harm.
- ❖ Family carers expressed the guilt they felt talking about this, of being disloyal to the person they cared for.
- ❖ Fear of the consequences of disclosing that they are experiencing carer harm was also a barrier.

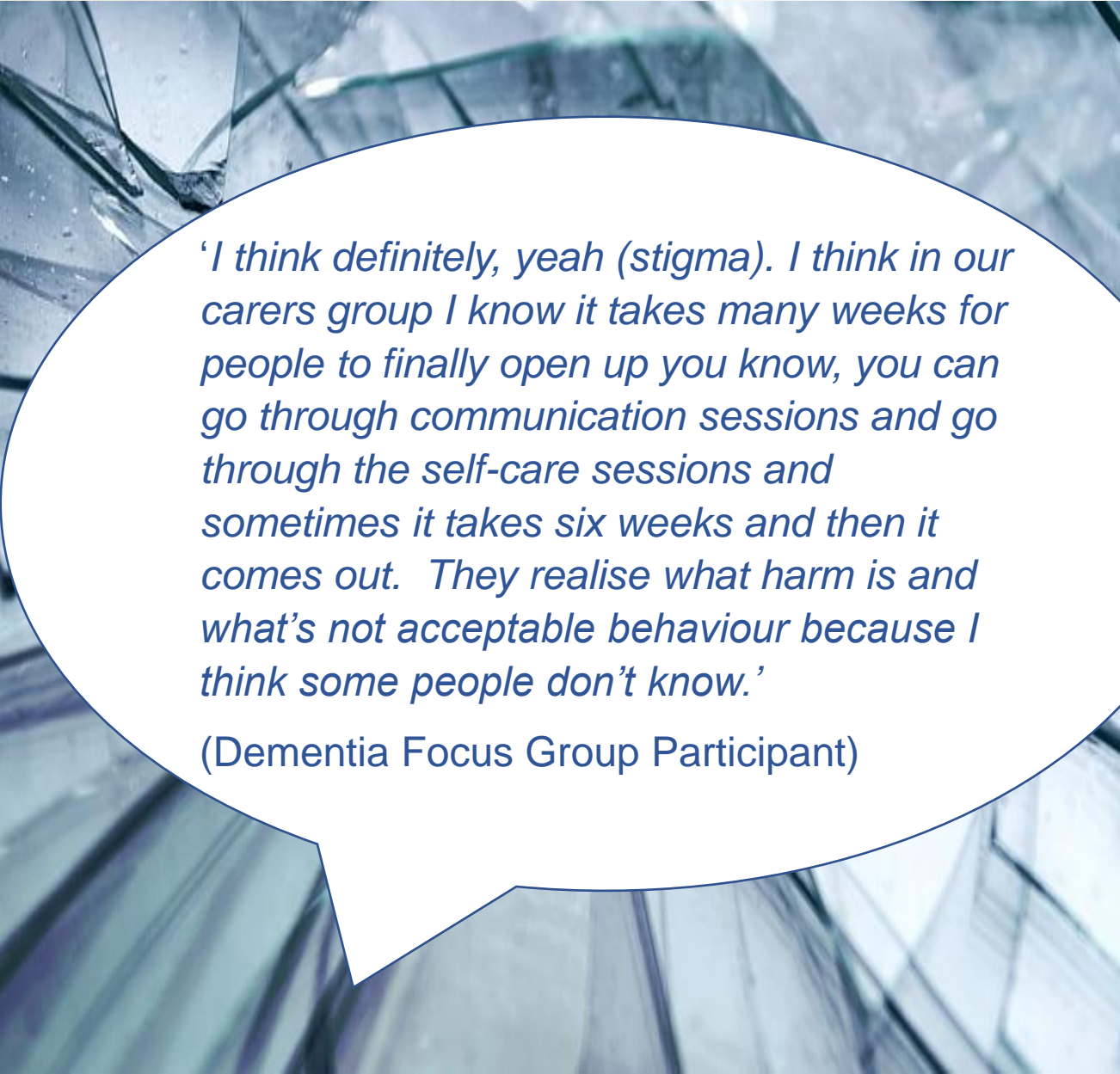
Shame, Stigma & Guilt

'We don't, carers don't talk about it. I think there's a huge stigma around...There's a huge silence. I mean I don't even, I haven't told most people what I've told you this morning, do you know, and even when I'm talking to other carers, we don't talk about that, you know. It's taboo, it is taboo.'

(Katrina, Autism Carer)

'I find that when I do have carers wanting to talk to me and share their experience they are very apologetic you know, please don't judge me...they feel they expect me to judge them because they are talking about that, despite trying to build this open relationship. So certainly, it's almost like it's guilt, so much guilt you know I should not be disloyal to my loved one by discussing this.'

(Dementia Focus Group Participant)



'I think definitely, yeah (stigma). I think in our carers group I know it takes many weeks for people to finally open up you know, you can go through communication sessions and go through the self-care sessions and sometimes it takes six weeks and then it comes out. They realise what harm is and what's not acceptable behaviour because I think some people don't know.'

(Dementia Focus Group Participant)

Takes time to
open up

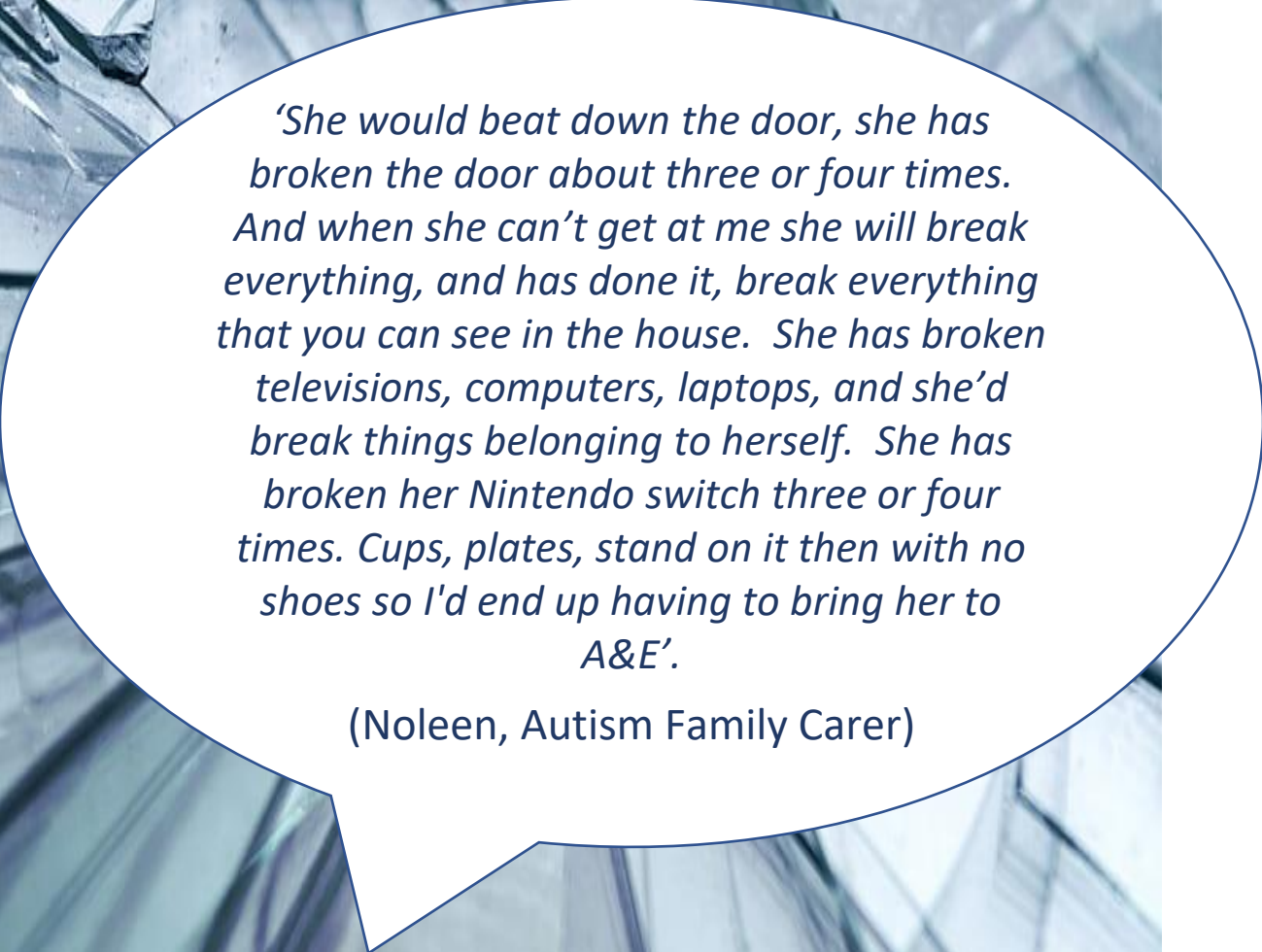


Types of Harm Experienced

Family carers spoke about experiencing a wide range of types of harm including 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.

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

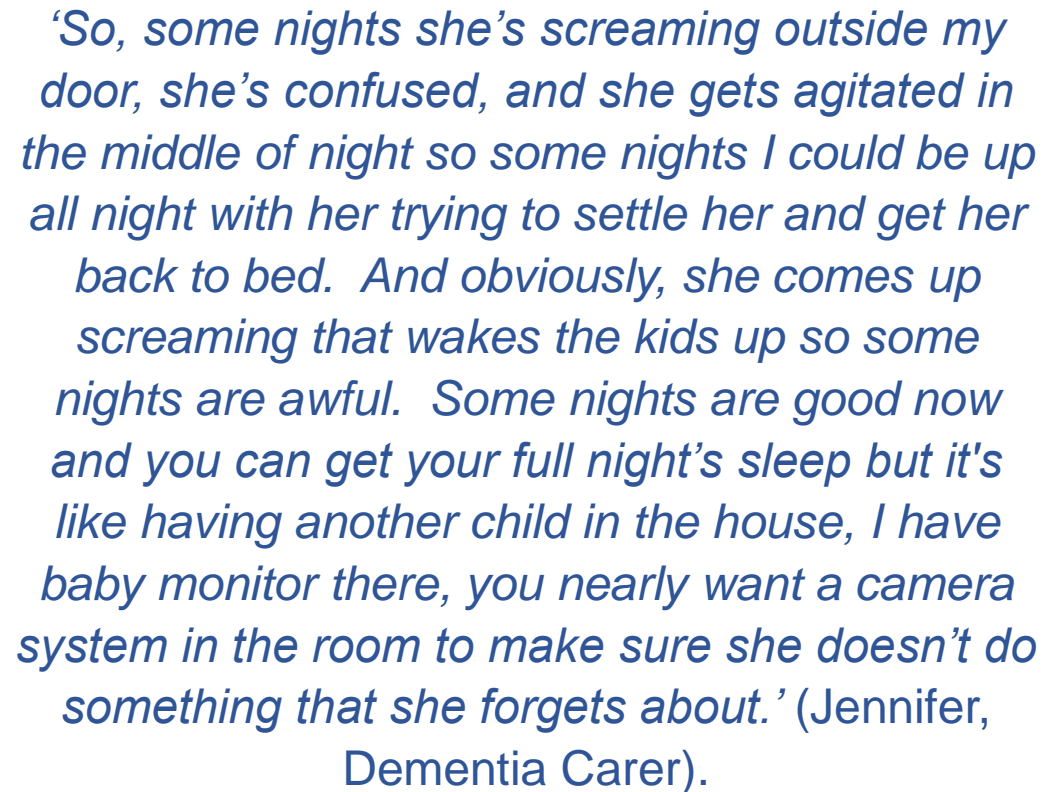
Professionals described the type of harm experienced by family carers: physical aggression/assaults emotional toll, impact on the family carers' mental health.



'She would beat down the door, she has broken the door about three or four times. And when she can't get at me she will break everything, and has done it, break everything that you can see in the house. She has broken televisions, computers, laptops, and she'd break things belonging to herself. She has broken her Nintendo switch three or four times. Cups, plates, stand on it then with no shoes so I'd end up having to bring her to A&E'.

(Noleen, Autism Family Carer)

Noleen's Experience of Carer Harm



'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. Some nights are good now and you can get your full night's sleep but it's like having another child in the house, I have baby monitor there, you nearly want a camera system in the room to make sure she doesn't do something that she forgets about.' (Jennifer, Dementia Carer).

Jennifer's Story

Impact of Covid19

'I think it really started to come up as a topic of concern in and around COVID when a lot of the day care centres were closed. So what prompted a lot of those behaviours that started to concern the care givers was the lack of supports that were in the community and like in the heart of COVID where families were locked up together 24/7...Patterns were broken, there wasn't consistency or scheduling and all those things that started exploding you know or escalating the number of issues where family carers were saying I don't feel safe in my home. Their child with autism or whether that was a parent with dementia it was across the spectrum where they had external supports previously in place and it started to really escalate to points of violence in some cases.'

(FCI Focus Group Participant)

Expectations, Responses and Systems that harm

- Participants reported the challenges of navigating a fragmented and complicated health and social care system.
- Diagnosis and early intervention- a critical juncture.
- Professionals spoke about the unrealistic and unhelpful societal expectations and pressures which were placed on family carers which were considered a contributory factor in the harm experienced.
- General expectation that the whole family will provide the necessary care, including other children in the family acting as caregivers i.e. young carers.
- The lack of clarity as to who is responsible for providing supports and services to autistic children and adults leads to many falling between services.
- Family carers recounted the experience of constantly having to 'fight' and 'beg for help' in order to stay safe.
- Many professionals reflected on their immense feelings of helplessness and frustration about their inability to respond, highlighting the link between carer harm and the absence of appropriate condition-responsive services.





Unrealistic Expectations of Family Carers

This perception, as I said, that's just "You're getting Carer's Allowance, so you've signed your life away." And exactly, exactly what does it mean to be a family carer? And you know, and I, I think of parents of children with additional needs, are really good at and vocalizing this...my child needs 24/7 care. It's amplifying those voices and kind of saying it, you know nobody can do twenty-four-seven care, and it's not that you're paid to work 24 hours a day, 7 days a week, you know.'

(FCI Senior Manager)

Navigating a Fragmented and Complex System

‘There’s no proper tracking, we are really frustrated, we get this all the time oh they have autism that’s great but that doesn’t mean they need disability, they are mild to moderate ID [intellectual disability] so they need to go to Primary Care [team]. Primary Care is saying no, that’s Social Inclusion you go to Social Inclusion, and they go no that’s Primary Care. If you look at the points they got for their ID that is actually moderate but we have people who have different scales of what’s mild and moderate.’

(Autism Focus Group Participant)

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**

Unhelpful Responses

'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, whether it was him, leave me alone, or whether it was a full-blown, you know, lashing out to the person. She got injured...And then the next day at four o'clock in the afternoon, I got a phone call from the director of, 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)

‘That sense of guilt and that sense of failure that sense of 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 again like my colleagues have been saying fear to go out of the home, fear of shame, all those pieces really resonate.’

(FCI Focus Group Participant)

Impact on Family Carers

‘So much is expected of carers, and I have to say like I really, really feel for the siblings. Because there are so many siblings out there taking full responsibility, I was only talking to a lady last week and like that has a child with quite complex needs and siblings who are very close in age. And her own situation is a single mother, those siblings are taking the responsibility to the point that they are missing days of college because they have to be with the brother. And that is just, just wrong in so many levels to have children looking after children is so wrong.’

(Autism Focus Group Participant).

Impact on Siblings(1)



Impact on Siblings(2)

'I had shown P (younger child aged 8) a safe path and a safety plan because this happened so many times. I used to say to P, it does not matter what happens to Mammy, your job is to open the front door whether it's through the sitting room window or the front door or back door. So we used to go through this all the time, and go into the neighbours next door and you get her to ring the Guards'

(Noleen, Autism Family Carer).

Impact on Siblings(3)

‘When D was about nine years of age, I was home on my own, my husband was in work and D came back from school and D had a tremendous meltdown and he pulled my hair even though he doesn’t usually do that, but that day he did. He was only eight or nine and he pulled me with such force that he pulled me on the ground and I hit my head on the ground and I was there for a few seconds. And then my eldest child came from school, so imagine D was nine so my eldest was eleven, can you imagine what it's like for an eleven year old child to restrain his brother on the sofa to give me the chance to get up. I remember this day to the day I die. Like my eldest was crying, he was saying Mammy I don’t know for how long more I can restrain him.’

(Lana, Autism Family Carer)

Impact on the Family Unit

'Those children grow into adults like we have no legislation, nothing to support us and I suppose like they remain at home the situation gets worse and then as X said we are then putting in safeguarding against the family because they are trying to protect themselves and by protecting themselves, I'm saying then I have to put in a safeguarding against you. And like we are a disability service, but we have no foster placements, no respite, we have nowhere for that person to go. And it's just, like for us it's frustrating and for those family members it's just exhausting, it's just like and then they get angrier with us because we are like where is this residential place, we have nothing to offer you. It's just, it's heart-breaking because you see the impact as you said it has on the children in the family, the adults in the family and the relationships.'

(Autism Focus Group Participant)

Responses that Harm (1)

'The poor guards they know C inside out, and they even have said to me that it's so unfair that you have no other choice but to ring us. That is what is on the Tusla website and their little card, in the case of emergency you ring the guards. And as they say they are not professionals to be able to do anything for C they can only calm down the situation. It's the Superintendent that makes the decision on the Section 12 and he doesn't take that lightly...I ended up in A&E with bruises and damages, four broken ribs and C was taken in by the guards on a Section 12. This is how C ended up in voluntary care. It was horrendous.'

(Noleen, Autism Carer).

Responses that Harm (2)

‘So you may have a parent who's living with dementia. Another child is their sole carer, respite is being offered, and the person with dementia will not accept anybody else into the house but the carer is completely burned out. They cannot continue to give care. And yet the person with dementia is unable to recognize that... People who have a very difficult relationship with their parents. Perhaps there is some trauma in the past or some abuse the parent then develops dementia, they come back into that relationship to care... And the carer is then in a very vulnerable position. And if they're stepping back, particularly if that parent had abused them in the past, whether that be physical or psychological or emotional and it creates a yeah, a very, very challenging dynamic for the care.’

(FCI Project Manager)



No way to
respond

'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)

What Helps?



World Café Questions

1. What terminology should we use to define the concept of carer harm/carers hurt?

2. How can we make the issue of carer harm more visible and what information could it be helpful for family carers to have?

3. How can professionals and service providers best support family carers experiencing carer harm? What strategies/interventions might be helpful?





What we co-designed in the World Café

One generic information and awareness raising leaflet on Carer Harm.

One autism specific and one dementia specific information and awareness raising leaflet on Care Harm

One 'Best Practice Considerations' document for Professionals and Service Providers.

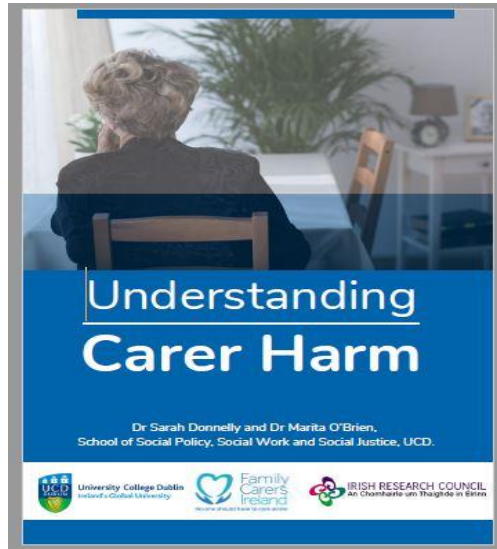
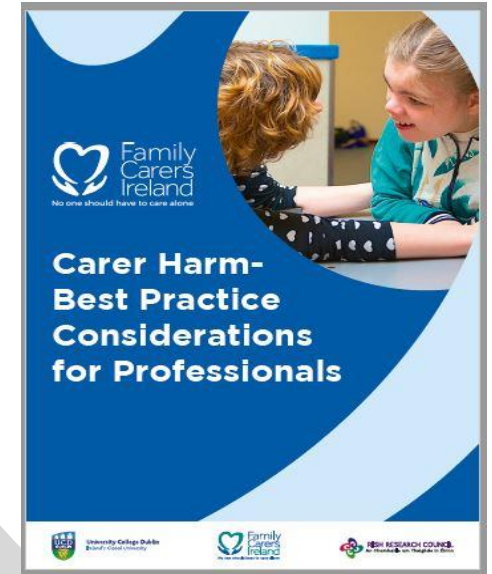


What Helps? (1)

- Advocacy was identified as critically important.
- The need for routine and proactive assessment of family carers' support needs, coping capacity and impact of caregiving on their physical and mental health.
- Collaboration, building links at the community level and signposting to enable resources to be pooled and avoid duplication including the setting up of referral pathways and services; utilisation of community-based expertise such as Gardaí (the police).
- Education and training: Provision of information and knowledge on the presenting disability or condition(s) is essential.
- Establishing peer support groups for family carers in communities was seen as hugely beneficial in providing a space to share concerns or experiences of carer harm.

What Helps? (2)

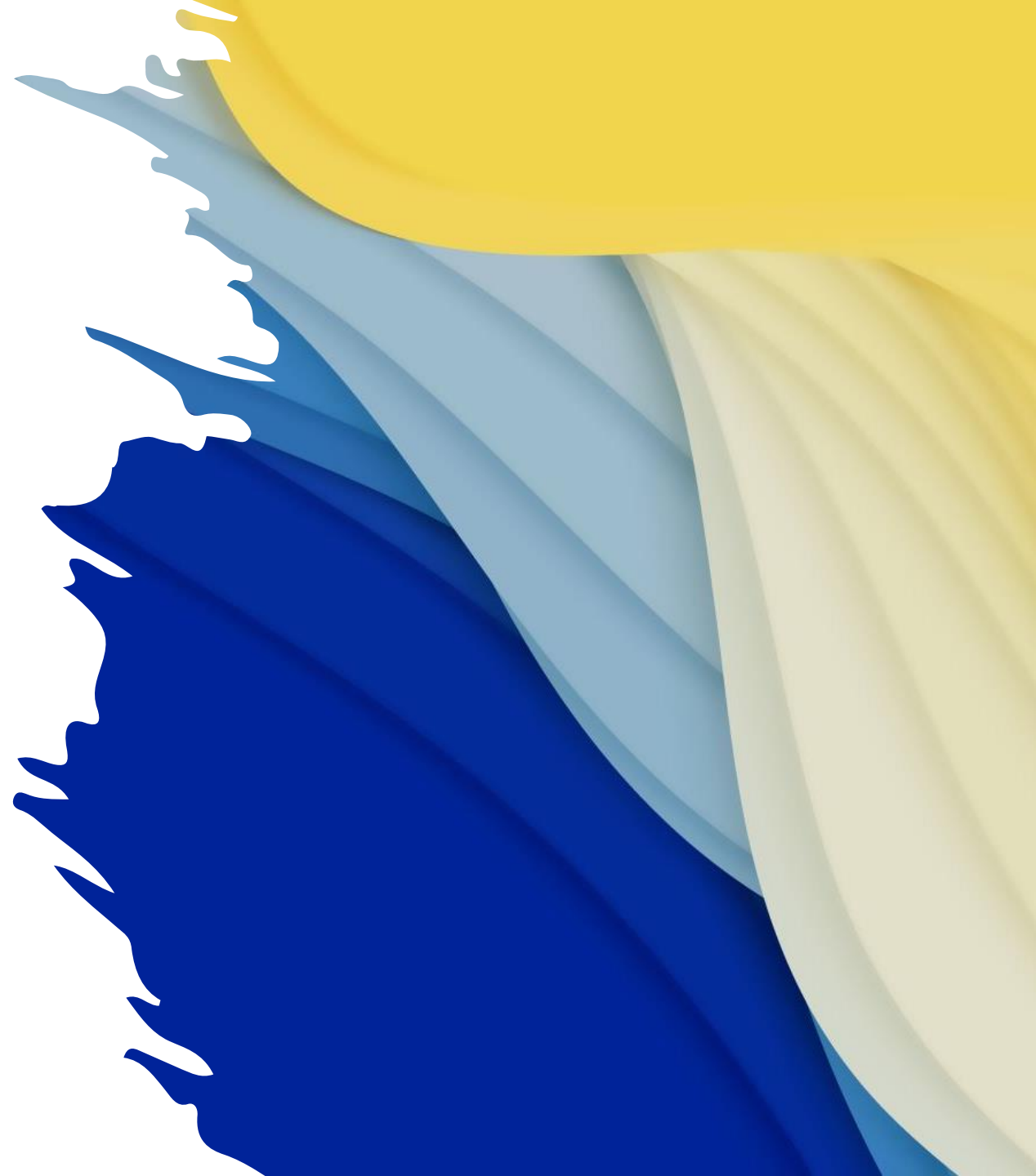
- Specific services were identified as crucial.
- For PLWD, provision of in-home respite and social care support workers. Referral to HSE Mental Health for Older Persons Service in a timely manner when the PLWD is exhibiting agitation/aggression.
- For autistic children, increased provision of early intervention and school places. The utilisation of the National Treatment Purchase Fund for the purchase of essential community services such as behavioural therapy, speech and language and occupational therapy were some suggestions.
- The provision of family therapy focusing on the whole family unit allows each family member to voice their worries, concerns and wishes.
- Make available counselling – help family carers work on boundaries, in terms of carer well-being, what they can reasonably expect of themselves; and how to hold boundaries in terms of others' expectations; this will help to manage their feelings of stigma, shame guilt, stress, and burnout.



Understanding Carer Harm Study Outputs



Discussion, Study Limitations and Conclusion



Discussion

- A diagnosis of autism or dementia did not automatically bring with it services for the child/adult being cared for or support for the family carer, even when family members were experiencing significant harm.
- Staffing and resourcing pressures result in services taking a 'silo' mentality, imposing strict diagnostic categories for access- families live with the risk of harm as the child/adult exhibiting the harmful behaviour is not getting any professional input.
- Failure in many instances to acknowledge and address that family carers, siblings, or other family members' right to live in a safe environment.
- Many parents who are assaulted by their children deny or minimise it or blame themselves for their children's behaviour. Parents fear blame from professionals who can either minimise or excuse the child's harmful behaviour (Coogan, 2012).
- Conflicts existed for many professionals in relation to balancing the needs, safety, and protection of all family members. The outcome of mandatory reporting concerning the safeguarding of children and mandatory referrals in relation to those defined as 'vulnerable adults' resulted in paperwork and stress for parents/carers but little meaningful action to protect or provide vital services and supports which would help to reduce eliminate risk and harm being experienced.

Discussion

- Need to revisit the terminology of 'carer harm' and consider alternatives, for example, 'carers who have experienced harm' or 'carers who have experienced harmful behaviours.'
- Parents/carers can feel immense shame and isolation, which prevents them from seeking support (Holt and Brennan, 2022).
- The lack of a legislative underpinning for the resourcing of disability assessments, a statutory entitlement to home care, and family carers' right to a standardised assessment of need in the Irish context is of ongoing concern.
- Effective protection and safeguarding needs to do more than simply wait for a situation to reach a crisis point (Keeling, 2017).
- Legislation has the potential to empower the agency of professionals. For example, a duty to provide assistance would enable professionals to put services in place, particularly where carers are struggling and under threat (Donnelly and O'Brien, 2022).
- Participants' experiences also suggest that we need to consider the more sophisticated concept of 'human interdependence' (Tronto, 1993, p.102) and the interdependent nature of everyday living and caregiving (Rabiee, 2013) when dealing with carer harm.

Study Limitations

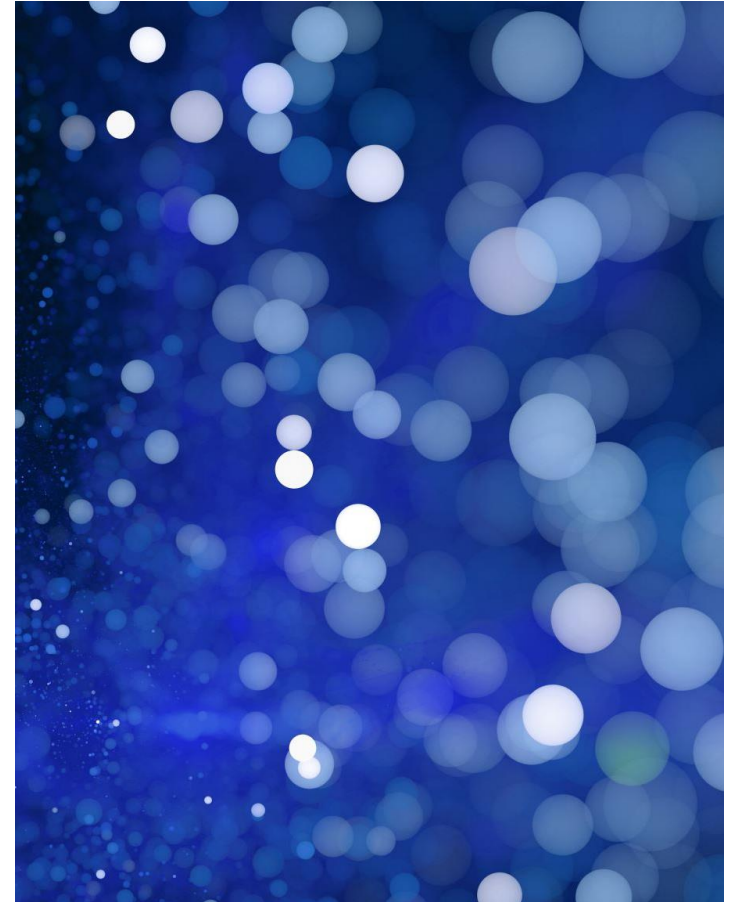
- This study is a small-scale exploratory study that used a purposeful sampling approach-non-representative and cannot be extrapolated to the wider population of family carers.
- Recruiting family carers who had experienced carer harm was challenging and this is reflected by our small sample of family carer participants.
- The findings are not generalisable to the practices and responses of all professionals and organisations in this field who are dealing with cases of carer harm.
- A significant limitation was the non-participation of the Gardaí (police) in the study despite strenuous efforts to recruit participants.
- Another limitation of the study is that findings relate to the Irish context where there may be cultural nuances and structural and systemic issues which are different to other jurisdictions.
- It would be beneficial if future work explored the views and experiences of a greater number of family carers and professionals. Such work could help to trace the shared and divergent experiences of family carers and professionals from an international perspective.

Conclusions

Carer harm remains a poorly understood and a taboo topic with uncertain and inconsistent responses from professionals and services. However, as our understanding develops, the hope that we can support family carers and the people they care for effectively and non-judgementally grows.

Continuing shame and fear of being blamed mean that family carers may not come forward for help until the situation is at a crisis point, and indeed they may not identify the problem as harmful or abusive themselves until this point - particularly where a child/adult's disability appears to be a significant cause.

Those who take on significant caring responsibilities and who experience carer harm should have certainty that the necessary services and supports will be provided in a proactive, preventative manner and that services will be in place to help them maintain their own health and well-being as well as that of their family unit.



Acknowledgements

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- A special thanks must also be extended to Sue O'Grady and Joanne Murphy for their help with the preparaton of the research report.
- We would also like to thank the many individuals who provided feedback on the draft booklets and in particular, the Alzheimer Society of Ireland Dementia Carer Campaign Network.
- I would like to thank our other Steering Group Members for their invaluable support and expertise.
- Finally, and most importantly, we would like to sincerely thank and formally acknowledge all of the family carers and professionals who participated in the study. Their participation has helped us to better understand what it is like to experience carer harm and the challenges related to supporting family carers who are being harmed.



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*Thank You for
listening and happy to
answer any questions.*

