



Understanding Carer Harm

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University College Dublin
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Family
Carers
Ireland

No one should have to care alone



IRISH RESEARCH COUNCIL
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Executive Summary

Background

The global challenge of ageing populations and increasing numbers of people requiring care mean that by 2030, one in five Irish people will be a family caregiver (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019). Family Carers Ireland (FCI) research carried out in 2019 surveyed 1,102 family carers, 90% of whom were female. Almost half (44%) of carers reported that they regularly experienced either physical aggression or verbal/emotional abuse as part of their caring role, with this being a particular challenge for family carers of people living with dementia (PLWD) and autistic children/adults. These findings shine a light on a hidden aspect of caregiving that is seldom discussed. 'Carer harm', where a family carer experiences intentional or unintentional harm from the child/adult they are trying to support or from professionals and organisations they are in contact with. To date, relatively little is known about the harm experienced by carers at the hands of the person for whom they care in an Irish context.

The aims of this research were to:

- Gain insights into the harm experienced by family carers who responded to FCI's 2019 survey by carrying out secondary data analysis (SDA) of the qualitative data set generated by the study.
- Explore the concept of carer harm from the perspective of family carers of autistic children/adults and PLWD, FCI support workers and other relevant professionals including social workers, nurses, educators, service providers and advocacy organisations.
- Develop and co-design information and education resources for family carers and FCI support workers and other relevant professionals in order to better understand, prevent and respond to family carers experiencing harm.

Research Design and Ethics

The project deployed an engaged research approach that focused on producing knowledge in collaboration with the project partner, family carers and professionals. The research design is mapped out over three work packages (WP).

WP1: Secondary Data Analysis (SDA) focused on analysing qualitative comments from family carers of autistic children/adults and PLWD relating to two questions within the 2019 survey, 1. 'Is there anything else you feel is important to carer health and wellbeing that is not covered in the questionnaire?' 2. 'Any other Training Needs?'

WP2: Narrative Interviews and Focus Groups set out to gain deeper insights into the lived experience of carer harm. Narrative interviews were undertaken with family carers of autistic children/adults, PLWD, educators and an FCI National Lead. To ascertain key stakeholders' understandings, working knowledge and current responses to carer harm, three online focus groups were held – one for FCI support workers, two online focus groups, one specific to autism professionals/stakeholders and one specific to dementia professionals/stakeholders.

¹ <https://www.mertonsab.org.uk/information-and-resources/carers/>

WP 3: World Café Workshop identified key content to be included in the information and best practice resources. A World Café Co-Design Workshop was held with family carers, FCI Staff, professionals, and service providers. The World Café approach enabled participants as knowledge holders and experts of their own lived experiences to engage with the material and findings from the narrative interviews and focus groups, encouraging cross-pollination of ideas and thinking.

The study received ethical approval from the Human Research Ethics Committee at University College Dublin.

Study Participants

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, 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.

Key Findings

The key finding from the secondary data analysis was the expression by family carers of their need for training on dealing with responsive or challenging behaviours. Three key themes (with subthemes for each) emerged from the analysis of the interview and focus group data.

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

Key findings in relation to understanding carer harm include:

- Difficulties with defining and understanding the terminology 'carer harm'. Participants reported how the term 'carer harm' is not instantly recognisable, nor is it well understood or regularly used in the everyday language of professionals or by family carers. This suggests the hidden nature of carer harm. Finding the 'right' terminology to reflect family carers' experiences of being hurt or harmed by the person being cared for is problematic, particularly within the context of unintentional harm.
- 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. Focus group participants highlighted a general lack of awareness from family carers as to what is and is not acceptable behaviour. Whether due to a lack of awareness or due to stigma and shame, family carers do not report or speak easily about the harm they experience in undertaking their caring role.
- Fear of the consequences of disclosing that they are experiencing carer harm was also a barrier. For many, their fears related to other children or family members being seen as 'at risk' and that unwelcome care alternatives or interventions would be imposed, for example, residential care.
- 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. They reflected on the 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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Dementia family carers spoke of living with verbal outbursts, verbal abuse, aggravation, aggression, and lack of sleep.

- Many of the autism family carers described living with the threat of harm on a daily basis, they never knew when a situation would deteriorate and they would experience assault or other types of harm for example, aggression and physical violence, psychological or emotional abuse and no sleep. Dementia family carers spoke of living with verbal outbursts, verbal abuse, aggravation, aggression, and lack of sleep.
- Family carers reported struggling to know how to manage presenting behaviours and for some, the professional advice given was not always seen as helpful or practical or the necessary advice was simply not provided.
- From the professionals' perspectives, focus group participants spoke about many different types of behaviours which they had encountered in their work which they understood to be carer harm. This included physical aggression, emotional toll, physical assaults as well as the impact on the family carers' mental health.
- Participants reported that family carers and the person they are caring for can also experience harm as a result of unrealistic expectations, pressures, and in how the broader health and social care systems treated them.
- Family carers commented on the harm caused or exacerbated due to lack of services and supports and in the way some healthcare professionals engaged with them. Professionals also spoke at length about this as well as the unrealistic and unhelpful societal expectations which were placed on family carers which were considered a contributory factor in the harm experienced.
- Professionals reiterated that there is a general expectation that the whole family will provide the necessary care, including other children in the family acting as caregivers i.e. young carers.
- There was also an expectation that family carers would cope with huge amounts of care alone in situations where professional carers would not be required to.
- Some family carers reported that they were 'forced to' abandon their autistic child/adult in order to access the supports their autistic child needed, but also to keep themselves and their other children safe. Others resorted to harnessing the help of politicians or the media to collectively advocate for essential supports and services.




2. Protecting Carers from Harm

To shed light on prevention and protective factors and considerations, the antecedents, the significant events or experiences that influence and shape carer harm experiences were identified.

- Diagnosis was identified as an important first step by family carers. Many described the experience of living and managing through a period of not understanding what was happening to the child/adult whether that was developmental delays, changes in their behaviour, or ability to function.
- For many of the family carer participants finding the answer to what was ‘wrong’ with their child/parent/relative or why they were acting differently was a long process and could take many years.
- Delays in receiving a diagnosis had consequences. For autistic children, often they missed out on early intervention; for PLWD they were not linked to supports so had no proper understanding or guidance on their specific type of dementia and how best to cope.
- Participants reported that a diagnosis of autism or dementia did not necessarily bring with it supports and services for the autistic child/ adult or the PLWD; nor support for the family carer.
- Family carers of children/adults with autism and autism professionals reported that early interventions (for example, early appropriate education) were critical to building a foundation for the autistic child’s future life chances and giving parents an understanding of autism, ways of communicating, and strategies for managing responsive behaviours.
- There was limited provision of early intervention or services for the PLWD or support for their family carer. Dementia carers reflected on how opportunities were not taken by professionals to address issues like agitation and responsive behaviours at an earlier stage, for example having the PLWD assessed by the Health Service Executive (HSE) Mental Health Services for Older People.

Family carers of children/adults with autism and autism professionals reported that early interventions were critical to building a foundation for the autistic child’s future life chances

- Many participants highlighted the need for awareness and increased supports at key transitional stages such as puberty (autism) and increasing or changing care needs (dementia). Autism family carers and autism professionals identified puberty as a particularly challenging time with the potential for increases in conflict, often resulting in carer harm. Reaching a stage, where family carers are required to provide more intimate care to the PLWD, can also be a trigger for responsive behaviour.
- Participants reported the challenges of navigating a fragmented and complicated health and social care system. The negative impacts on family carers and the person they were caring for when unable to access the appropriate, condition-specific services, were repeatedly highlighted.
- 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, when providing assistance for certain tasks, such as changing incontinence pads. Yet, service providers were able to walk away from undertaking the same task when staff were deemed to be at risk.
- Autism and dementia professionals spoke at length about their difficulties as health and social care professionals when trying to provide the necessary help and support within the confines of how current systems are structured and function. Many 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.
- Some reported that they had no ability to respond appropriately, even to crises referred to them, e.g., no emergency foster care, respite, or residential places.
- Professionals reported feeling 'useless' working in a context where there was little acknowledgement that protecting carers from harm is extremely difficult, particularly in circumstances where the necessary legislation or appropriate services and supports cannot be accessed.



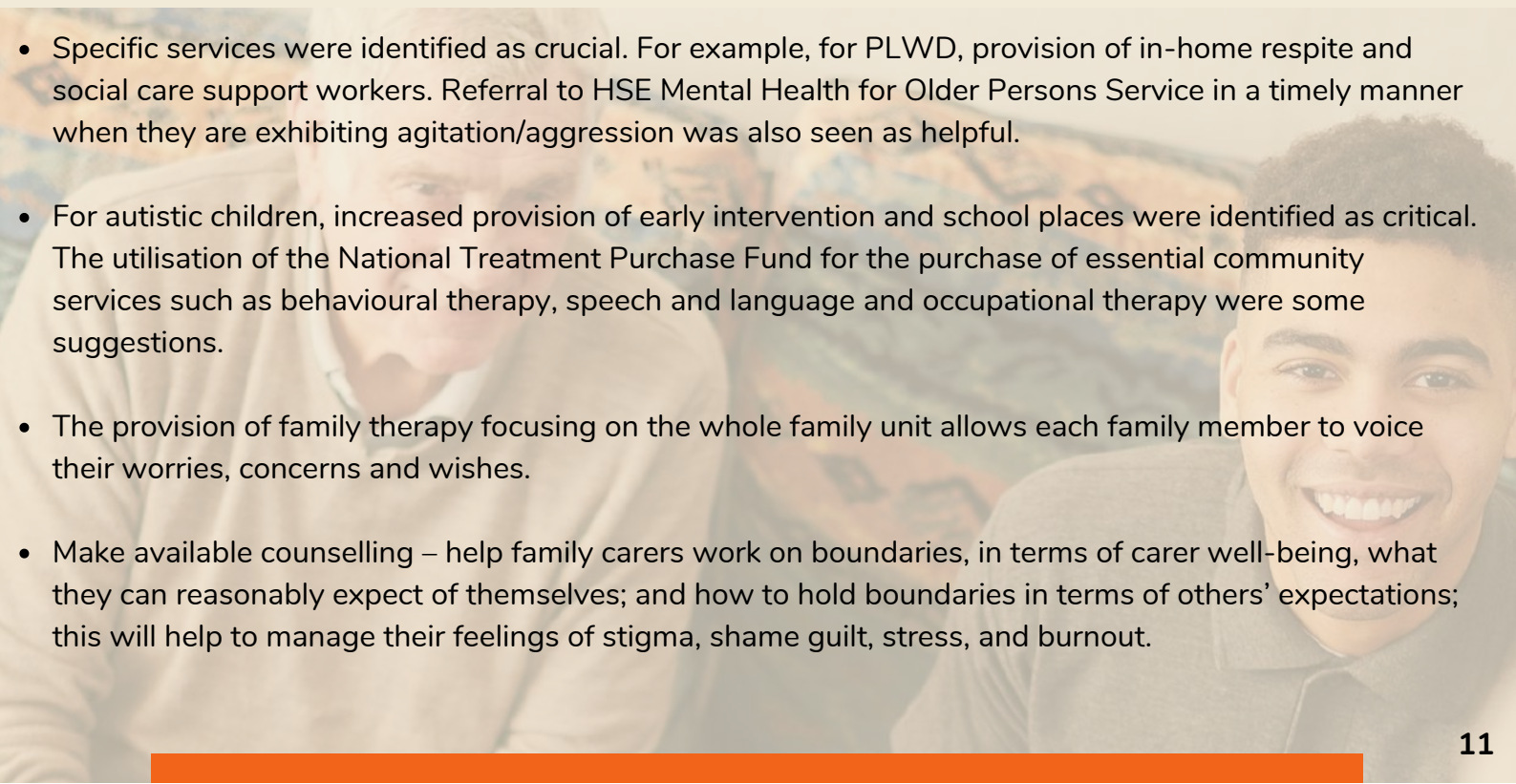
The lack of clarity as to who is responsible for providing supports and services to autistic children and adults leads to many falling between services.



3. What Helps?

Family carers and professionals had many ideas concerning what can help in situations of carer harm and also suggestions about what works from their own experiences. These included:

- 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.
- Specific services were identified as crucial. For example, 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 they are exhibiting agitation/aggression was also seen as helpful.
- For autistic children, increased provision of early intervention and school places were identified as critical. 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.





World Café Findings

World Café co-design sessions to inform the content of Carer Harm information leaflets centered around three core questions:

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

It was concluded that the outcome of behaviour, whether intentional or unintentional, that caused harm had to be 'named' if family carers experiencing harm were to identify themselves, disclose the harm and get support. It was suggested that the information leaflets should include a definition of 'carer harm'.

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

The responses focused on:

- Professionals engaging with family carers to routinely and proactively ask about 'carer harm', making it part of 'normal' conversation.
- Inclusion of carer harm as a topic in education and training courses for family carers and as part of standardised assessment forms and when discussing symptoms at diagnosis.
- Inform family carers of what to do if they are experiencing carer harm and encourage them to reach out for support. Information on services including advocacy services is important.
- Raising awareness of carer harm among health and social care professionals as well as GPs, Public Health Nurses, Primary Care teams and wider community stakeholders including the Gardaí.

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

Participants acknowledged that the scarcity of services and supports they can offer made it very difficult to support family carers. However, they did identify:

- Services and supports that would support family carers and help prevent carer harm including respite services, after-school clubs, and youth clubs for autistic children/adults; social clubs for PLWD; the facilitation of carer peer support groups in parallel with day services.
- Having a named person/body responsible for signposting autism and dementia services and support to prevent service users and family carers from being referred to different services without success.
- Provide funding for individualised, tailored, preventative services and supports.
- Strive to remove the 'hero' narrative around family caregiving. Acknowledge the multidimensional and complex nature of carer harm.

Introduction and Methodology

Introduction

The global challenge of ageing populations and increasing numbers of people requiring care mean that by 2030, one in five Irish people will be a family caregiver (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019). Family Carers Ireland (FCI) research carried out in 2019 surveyed 1,102 family carers, 90% of whom were female. Almost half (44%) of carers reported that they regularly experienced either physical aggression or verbal/emotional abuse as part of their caring role. The study findings also suggested specific challenges for family carers of people living with dementia (PLWD) and autistic children/adults.

These findings shine a light on a hidden aspect of caregiving that is seldom discussed. ‘Carer harm’ occurs 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). It can also relate to harm experienced from professionals and organizations family carers come into contact with².

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 harm (FCI, 2019). For example, spousal caregivers of partners with dementia who display aggressive behaviour often report lacking support and feeling isolated and vulnerable in the face of dementia-related intimate partner violence (Tyrrell et al., 2016).

Adult safeguarding as a concept is often interpreted solely as a response to harm or abuse, yet it can also be viewed in terms of a preventative and reactive process. To date, relatively little is known about the harm experienced by carers at the hands of the person for whom they care and there is a significant stigma and shame associated with disclosing this type of harm. Safeguarding means putting measures in place to promote and protect people’s human rights, their health and wellbeing, and empowering people to protect themselves (Donnelly and O’Brien, 2019). However, we know that, in the Irish context, almost a quarter of people would not know who to report adult harm or abuse to if they or someone they knew was a victim of neglect or abuse (Safeguarding Ireland, 2020). There is also low awareness of HSE Safeguarding and Protection Teams as a place to report harm, abuse, or neglect (Sheehan and O’Sullivan, 2021).

Furthermore, challenges are often faced by social workers and other professionals when care and violence intersect, for example when a service user is the alleged perpetrator of abuse against their family carer, particularly concerning those caring for family members with mental health difficulties, acquired brain injuries and dementia (Donnelly and O’Brien, 2019). Practitioners often struggle to engage with families’ testimonies about harm in the context of care and illness and there have been calls for all stakeholders to work more proactively and in partnership with families where care and harm intersect (Isham et al., 2020).

² <https://www.mertonsab.org.uk/information-and-resources/carers/>

Research Aims

- To carry out secondary data analysis (SDA) of an existing qualitative data set generated by FCI in order to gain deeper insights into the lived experience of family carers experiencing harm by the person they care for.
- To explore the concept of carer harm from the perspective of family carers of PLWD and autistic children/adults, FCI Support Managers and other relevant professionals including, social workers, nurses, educators, NGO's, and advocacy groups³.
- To develop and co-design information and education resources for family carers and professionals coming into contact with carers in order to better understand, prevent and respond to carer harm.

Research Design and Ethics

The research design is mapped out over three work packages (WP) combining a multimethod, codesign, and partnership approach. As engaged and participatory research, and given the scope, the project does not strive to produce representative conclusions vis-à-vis family carers as a population.

Instead, the focus is on beginning to improve our understanding of the lived experience of carer harm and the production of knowledge in collaboration with the partner organisation, Family Carers Ireland, with a view to enhancing their capacity to respond to the issues associated with family carers experiencing harm.

Several planning meetings were held with FCI staff who have responsibility for all organisational child protection and adult safeguarding issues to agree on the sample size and targeted participants for the narrative interviews and focus groups.

Steering Committee members also provided valuable guidance and advice on sampling and participation.

³ Secondary data analysis identified a significant number of responses related to carer harm from family carers of autistic children/adults and carers of people living with dementia. After consulting with our Steering Group Members, it was agreed the main study should focus specifically on these two cohorts of family carers.



Research Questions to be Explored

1. What are the perceptions and experiences of family carers of carer harm by the person they are caring for?
2. How can professionals and service providers better support family carers who are experiencing carer harm?

Project Management

An Expert Steering Committee was established to provide additional expertise and support to the project. The committee met two times over the course of the project and had oversight of every stage of the research process.

Steering Committee Members included:

- Dr Nikki Dunne, FCI Senior Research Manager
- Pearl Crosby, FCI Quality and Safety Manager
- Mary Ryan, Dementia Nurse Specialist
- Dr Deirdre O'Donnell, Assistant Professor, UCD Health Systems.
- Professor Alisoun Milne, Professor of Social Gerontology, University of Kent
- Celine O'Connor, Principal Social Worker, HSE Adult Safeguarding and Protection Office, Dublin South, Kildare & West Wicklow Community Healthcare

Ethical Issues

There are ethical implications and sensitivities in interviewing people who have been subjected to any form of harm, abuse, or violence. In addition, researching the issues of carer harm by another family member demands that particular attention must be given to protecting the safety and confidentiality of the participants.

All participants prior to the interview/focus group/world cafe received written information before agreeing to participate. We strived to ensure that the utmost care was taken in obtaining informed consent and that all research participants were fully aware of what was involved in the data collection process. At the beginning of the interview/focus group/world cafe, an explanation of the study was provided verbally, and all participants were given the opportunity to ask questions. All interviews and focus groups were audio-recorded. Verbal consent was taken at the start of the recording, and no participants declined to be recorded. All audio-recordings were transcribed verbatim. Transcripts were read in alongside audio-recordings to ensure the quality of the transcription. The management of research data met with the requirements set out under GDPR and Irish data protection legislation. The study, therefore, followed strict ethical guidelines concerning data anonymity and confidentiality.

Researchers also observed for any potential indications of distress during narrative interviews, focus groups and the World Café workshop. A comprehensive distress protocol was developed and adhered to.

The study received ethical approval from the Human Research Ethics Committee at University College Dublin.

Recruitment of Family Carers

A full assessment of the family carer's circumstances was carried out by an FCI support worker/manager who has knowledge of the person before they were approached to participate. An assessment was made in relation to the:

- physical and psychological well-being of the person
- present level of safety and security
- length of time they have been accessing support services
- English language capacity and cognitive capacity

As part of our ethical approval process, it was agreed in relation to all participants that if any participant reported practices not complying with the laws in force, they will be re-directed to their employing organisation and/or child welfare and protection/ safeguarding authorities.

Sample Size and Inclusion Criteria

A purposeful sampling approach was employed. Purposeful sampling involves identifying the cases, individuals, or communities best suited to help answer the research questions posed (Campbell et al.2020). FCI acted as a gatekeeper and assisted with identifying and recruiting family carers of autistic children/adults and PLWD who self-identified to their service as experiencing/having experienced carer harm and who have been or currently are in receipt of FCI support services.

Recruitment involved FCI approaching family carers who met the inclusion criteria of:

- (i) self-identified as being a family carer who has experienced carer harm
- (ii) being a family carer of a PLWD or an autistic child/adult
- (iii) have the cognitive capacity to engage in a narrative interview

The researchers also agreed to share, by email, the draft report, information leaflets and best practice considerations with the interview focus group and World Cafe participants, before them being made available in the public domain. This helped to ensure that participants had an opportunity to voice any concerns about the presentation and interpretation of the findings, and to ensure anonymity.

The sample size was negotiated with FCI staff keeping in mind the study research questions, aims and objectives and findings. The sample size is not intended to be statistically representative rather it is sufficient to reveal: the diversity of participant views and experiences; to gain insights into the lived experience of carer harm; explore how professionals currently respond and to develop awareness raising and information materials to improve both preventative and intervention/response measures.



Methodology Utilised

The study deployed an engaged research approach that focused on producing knowledge in collaboration with the project partner, family carers and professionals. The research design is mapped out over three work packages (WP) combining a multimethod approach that uses secondary data analysis, qualitative exploration, and co-design, as now described.

WP1 Secondary Data Analysis (SDA)

Given the ethically sensitive nature of the study topic, and the short timescales involved, it was decided in the first instance to use SDA to gain a more in-depth understanding of family carers who have suffered harm utilising the unanalysed qualitative data set from Paying the Price: The Hidden Impacts of Caring (FCI, 2019). Written permission to access the data set was granted by FCI. Qualitative comments from two key questions within the 2019 survey were analysed:

1. 'Is there anything else you feel is important to carer health and wellbeing that is not covered in the questionnaire?'

2. 'Any other Training Needs?'

All responses to Question one were analysed and coded generically. The analysis and coding for Question two focused only on comments from family carers of autistic children/adults and comments from family carers of PLWD. This helped access valuable, deeper insights and a nuanced understanding of family carer experiences of carer harm.

WP2 Narrative Interviews and Focus Groups

In order to complement the findings of the SDA, it was agreed that it would be helpful to carry out a small number of narrative interviews in order to gain deeper insights into the lived experience of two specific groups who featured prominently in the data; family carers of autistic children/adults; and family carers of PLWD who have experienced carer harm.

Narrative interviews were carried out with five family carers of autistic children/adults and four family carers of PLWD who self-identified as experiencing carer harm and/or who are in receipt of FCI support services. Participants were given the option of their interview taking place either online or face-to-face. Initial discussions with FCI staff indicated that many family carers are still quite anxious about Covid-19, and it was likely that their preference would be for online interviews.

As some professionals were unable to participate in the scheduled focus groups, a narrative interview was also carried out face-to-face with two educators working with autistic children and an online narrative interview with an FCI Senior Manager.

A purposeful sample was utilised to convene one online focus group with FCI Support Managers, a FCI Senior Manager, a FCI Regional Manager and two online focus groups with other relevant professionals/stakeholders. The information gained from the focus groups helped to ascertain key stakeholders' understandings, working knowledge and current responses to carer harm. This data then helped to inform the themes and questions to be explored during the World Café Workshop.

WP 3 World Café Workshop

A World Café co-design workshop was held with family carers, FCI Staff, professionals, and service providers. A World Café approach focuses on an intimate exchange, and disciplined inquiry to encourage the cross-pollination of ideas and possibility thinking. In a World Café, all participants are regarded as experts of their own lived experience and knowledge. There is no pressure to reach a consensus, as diverse perspectives are encouraged and valued (MacFarlane et al., 2020).

By using the World Cafe methodology, workshop participants became engaged with the material and findings from the narrative interviews and focus groups to identify key content to be included in the information and best practice resources. The workshop explored the learning needs and readiness of professionals to have conversations and make interventions in cases of carer harm. It also enabled reflection upon contextual factors such as culture, values and norms which influence perceptions, practice, and responses in relation to carer harm and abuse.

In conclusion, it is argued that these methods were appropriate to ascertain family carers and key stakeholders' experiences, working knowledge, and existing understandings of working with carer harm processes in the Irish context.

Data Analysis Approach

Secondary Data Analysis (SDA): Qualitative comments from two questions in the 2019 study underwent an SDA process. The comments of respondents who were carers of an autistic child/adult and carers of PLWD were analysed to discern the number of responses/comments. These were then read and analysed thematically to generate emergent common themes.

Narrative Interview Data: Narrative analysis was used to explore participants' stories as knowledge through the 'social reality of the narrator' (Etherington, 2004:81). This process helps convey a sense of the person's experience in its depth, messiness, richness, and texture, by using the actual words spoken. It is important to acknowledge the role of the researcher in this conversational process in order to be transparent about the relational nature of the research, and the ways in which these stories are shaped through dialogue and co-construction, as well as providing a reflexive layer with regard to the researcher's positioning.

Focus Group Data: Thematic analysis was used; an appropriate method for identifying and analysing patterns of meaning (Braun & Clarke, 2006). It is a flexible method which can be applied methodically and rigorously to search for meanings and patterns within interviews. The method involves verbatim transcripts; thorough immersion in and familiarisation with the data; the generation of codes; and the identification of themes and sub-themes. This in turn leads to an overall narrative account that can inform findings and discussion of findings (Lyons & Coyle, 2015).

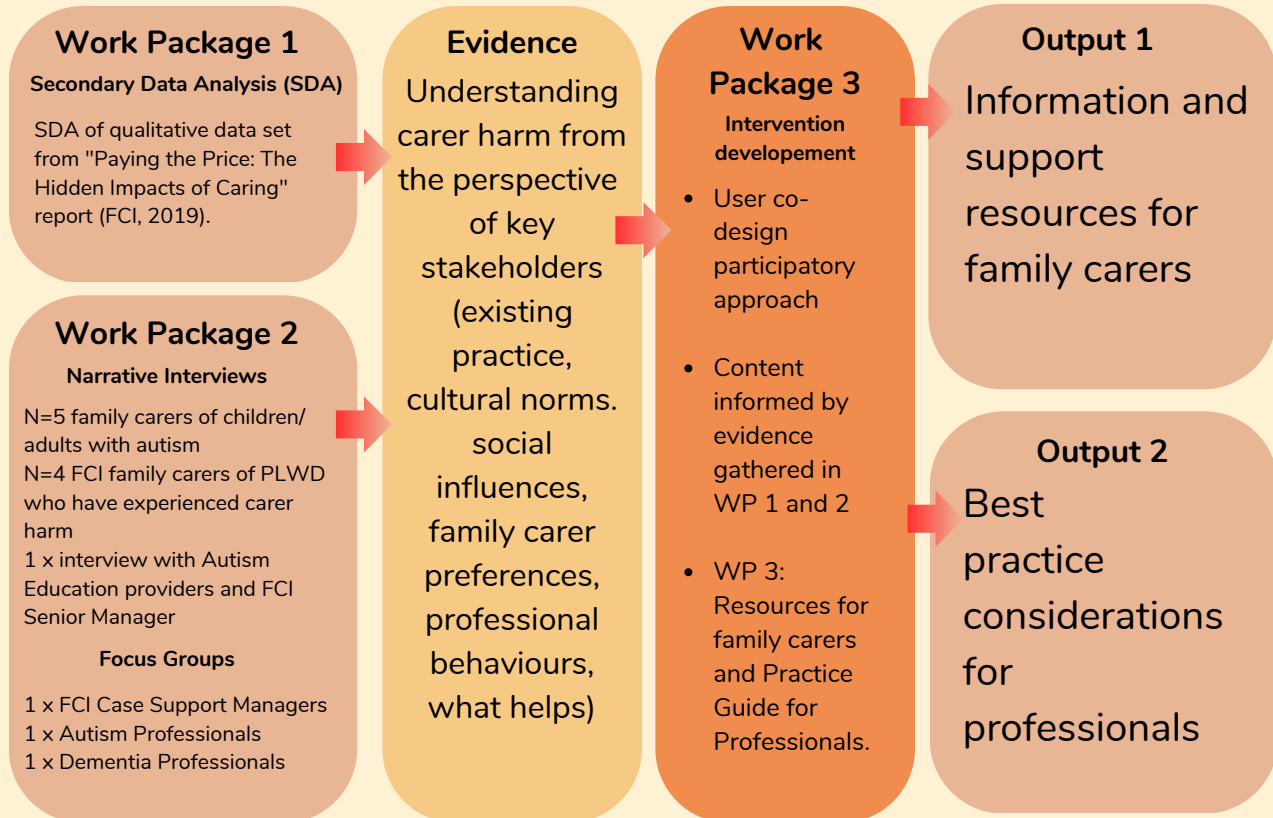
A two-step process was used in the data analysis process and coding: (1) initial open in vivo coding and (2) aggregation of in vivo codes and abstraction into higher-order themes. All the interviews were coded into the lower order in vivo codes independently by both researchers (MOB and SD). Discrepancies between the two researchers were discussed and resolved at weekly meetings.



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?





Findings

Secondary Data Analysis Findings

Initial analysis of the qualitative data set highlighted that the majority of responses related to two main groups of family carers: family carers of autistic children/adults and family carers of PLWD, generated by two key questions:

1. 'Is there anything else you feel is important to carer health and wellbeing that is not covered in the questionnaire?'

Question 1 which related to other aspects of carer health and well-being received 328 qualitative responses. Within the SDA process, responses were coded under six broad themes of:

- Need for information and advice on entitlements and financial assistance
- Need for increased respite
- Isolation and the need for more support
- Need for more psychological support and counselling.
- Education and support on family relationships and conflict and how they impact on caring relationships
- Self-care.

2. Any other Training Needs?

Question 2 related to other training needs identified by family carers. Of the 734 qualitative responses received for this question, 434 responses were from family carers of an autistic child/adult and 166 responses were from family carers of PLWD.

Participants identified a wide range of general training needs. Many participants expressed a need for further training on dealing with responsive or challenging behaviours:

I need training on how to protect myself from getting hurt during my child's violent behaviour and how to prevent the person you are caring for hurting themselves during a violent outburst.

Autism Family Carer, 2019 Survey Respondent

Other participants highlighted the need for training in helping to cope with difficult dynamics or conflict within the family unit:

Managing time or dealing with family dynamics when the person being cared for takes up a lot of the focus.

Dementia Family Carer, 2019 Survey Respondent

Training Needs Identified by Family Carers of Autistic Children/ Adults

433 qualitative responses were analysed and coded under 5 key themes:

- How to care for a child with a disability
- Communication training
- Behavioural training
- Need for training on autism and sensory processing
- First aid and manual handling.

Many respondents expressed a need for specific education or training on how to care for a child with autism. One respondent wrote:

"How to care properly for my child. How to deal with emotions coming up to teenage years".

(Autism Family Carer, 2019 Survey Respondent)

Other respondents highlighted the need for training on how to communicate with people who are non-verbal, training on alternative communication methods and specific speech and language therapy training,

"How best to respond to my son's needs. He is non-verbal. Would love someone to come into my home and show me how to best care for him to meet his needs".

(Autism Family Carer, 2019, Survey Respondent)

A large number of respondents also expressed the need for more behavioural training that would help them to better respond to and cope with responsive behaviours:

"Dealing with autism meltdowns. Teaching other members of the family how to deal with it".

(Autism Family Carer, 2019, Survey Respondent)

Some respondents communicated the need for education and training on autism and sensory processing workshops:

" I need more training in OT (Occupational Therapy) particularly sensory processing. "

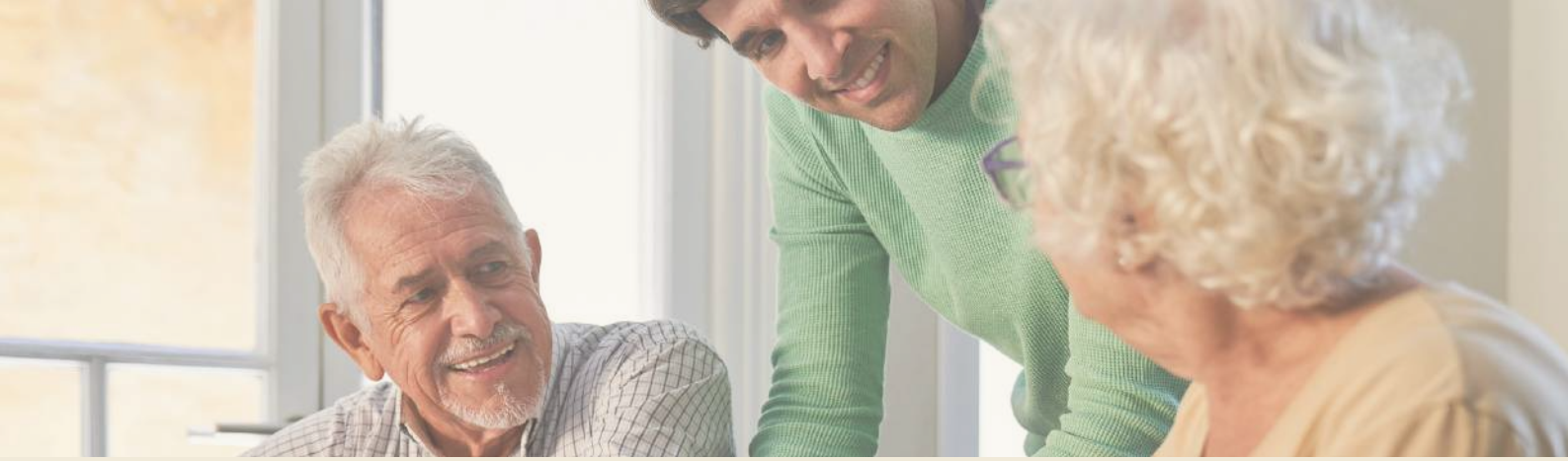
Autism Family Carer, 2019 Survey Respondent

Many Autism family carers also expressed the need for first aid and manual handling training:

"First aid and manual handling when lifting a 30kg child".

(Autism Family Carer, Survey Respondent)

Autism and dementia carers identified key areas for training that would help to better support them in their role as family carers. Both sets of respondents identified the need for condition-specific training, training on supporting communication, manual handling and dealing with responsive behaviours.

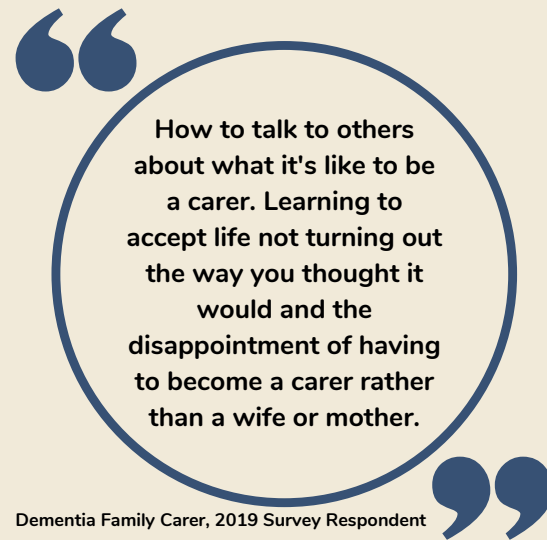


Training Needs Identified by Family Carers of People Living With Dementia

166 qualitative responses were analysed and coded under five key themes:

- Health and well-being of the carer
- Challenging Behavior Training
- Manual Handling
- Stimulation and managing mood swings
- Dementia specific training

Many responses related to the need for training around protecting the health and well-being of the carer. One respondent noted:



Dementia Family Carer, 2019 Survey Respondent

Many dementia carers identified the need for more challenging behaviour training:

"Help for when he is aggressive - some sort of self-protection training".

(Dementia Family Carer, 2019 Survey Respondent)

As with some autism carer responses, a large number of respondents highlighted the need for more manual handling training:

"To be better informed regarding issues surrounding my mother's health/condition and to be trained in handling her mobility issues better".

(Dementia Family Carer, 2019 Survey Respondent)

Some dementia carers stated they needed training in effective ways of stimulating the person they were caring for and how to deal with mood changes:

"I'm not a nurse but I really feel I require some qualifications to help in caring for my husband during the day".

(Dementia Family Carer, 2019 Survey Respondent)

Finally, a large number of the responses related to the need for dementia-specific training for carers. One respondent wrote:

"How do I recognise UTI (urinary tract infection), serious chest infection, other ailments? How do I calm agitation? How do I think on my feet, deal with my own stress levels in the moment".

(Dementia Family Carer, 2019 Survey Respondent)

Narrative Interview and Focus Group Findings

Narrative interviews were held with five family carers of autistic children/adults and four family carers of PLWD who self-identified as having experienced carer harm. They took place between September 2022 and January 2023 and lasted between 21 minutes to 75 minutes. The profiles of the study participants (names anonymized) are presented in the following tables:

Table 1: Autism Interview Participants

Autism Family Carer	Relationship to Care Recipient
Katrina	Mother to 2 autistic sons
Paula & Sean	Parents to autistic son (12yrs)
Valerie	Mother to autistic son (12yrs)
Noeleen	Mother to autistic daughter (12yrs)
Lana	Mother to autistic son (17yrs)

Table 2: Dementia Interview Participants

Dementia Family Carer	Relationship to Care Recipient
Patrice	Wife
Mairead	Daughter
Jennifer	Daughter
Oonagh	Daughter

Table 3: Professional Interview Participants

Type of professional	Gender
FCI Senior Manager	F
Educator 1	F
Educator 2	F



Focus groups were held with FCI staff, autism professionals and dementia professionals with each focus group having 4-5 participants. They took place between November 2022 and December 2022 and lasted between 100 minutes to 120 minutes. The profiles of the study participants are presented in the following tables:

Table 4: FCI Staff Focus Group Participants

Type of professional	Gender
FCI Support Manager 1	F
FCI Support Manager 2	M
FCI Support Manager 3	F
FCI Support Manager 4	F
FCI Senior Manager	F

Table 5: Autism Professionals Focus Group

Type of professional	Gender
Principal Social Worker- Child and Adolescent Mental Health Team	F
Tusla, Child and Family Agency Social Worker	F
Principal Social Worker, HSE Adult Safeguarding and Protection Team	F
Disability Service Provider Social Work Team Leader	F

Table 6: Dementia Professionals Focus Group

Type of professional	Gender
Dementia Nurse	F
Senior Medical Social Worker	M
Alzheimer Society of Ireland Dementia Advisor	F
Advanced Nurse Practitioner, Memory Assessment & Support Service	F

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'

Carer Harm - how to define it?

Theme one, 'Understanding Carer Harm' helps us to answer the first research question which set out to advance an understanding of carer harm from the perspective of family carers, professionals, and service providers. Participants discussed the difficulty with defining and understanding what is meant by the term 'carer harm.' This topic generated more discussion from professionals, whereas family carer narratives tended to focus more on their experiences of carer harm rather than how it is defined and understood. Professionals discussed the difficulty of finding the 'right' terminology to reflect family carers' experiences of being hurt/ harmed when providing care and queried the appropriateness of the term 'carer harm.'

“Some people I find would never describe it as carer harm, they would never use the word like I feel.”

FCI 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 Focus Group Participant

A dementia family carer reflected on their discomfort with the use of the word 'harm' and suggested that 'behaviours that challenge' or 'behavioural and emotional expression of need' could be other terminologies to consider. An educator had expressed similar sentiments about the use of carer harm:

"But in relation to carer harm, I don't like that term...if you say 'it harms' it does suggest intent but I don't know how else you would put in it".
(Educator Interview Participant)

A dementia professional in the focus group highlighted the need to consider what we mean by 'harmful' while an autism focus group participant reflected that the term 'carer harm' is not instantly recognisable by professionals or service providers suggesting the hidden nature of these experiences:

"I think the word harmful is really important to tease that out, it's either the symptoms of dementia, the cognitive symptoms or the non-cognitive symptoms of aggression and agitation or it's the nature of the care itself having to give personal care to your husband who is 53 or you know those acts that people have to do. The burden of care like unmanaged faecal incontinence that kind of poor I suppose coordination of care services leads people to harm I think. Not just the symptoms of dementia but the things that people end up having to do, to support the person". (Dementia Focus Group Participant)

“ We are seeing a lot more of it. I suppose we probably wouldn't have... our staff wouldn't have recognised it as carer harm and I think it's becoming more and more apparent in terms of our ageing population of carers...I suppose our carers are now beginning to age and I suppose some of their family members, their behaviours maybe are increasing at home. ”

Autism Focus Group Participant

The majority of participants believed the term was problematic in that it was not well understood or regularly used in the everyday narratives of family carers or by the professionals who were supporting them.

Participants involved in delivering dementia education or training sessions commented on the length of time it took for carers to open up about their experiences of harm, and the setting up of the group that seemed to make it easier to speak about these experiences:

"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)

Participants discussed the difficulty in finding the right language to express the harm experienced by family carers, in terms of wilfulness or intentionality. One educator commented on the presenting behaviour in the school environment sometimes being related to a student's needs and not being deliberate:

"We've never really referred to it as carer harm, no. But we do have a number of students here in the school who would present with behavioural needs and would exhibit maybe physical force sometimes when they're in a zone of distress or feeling dysregulated. And it's not deliberate the harm that they might cause or inflict on another staff member or another student, it's not deliberate but it's just born out of their own need".

(Educator Interview Participant).

Other participants suggested that the term carer harm could be considered offensive or insulting to family carers and the person they are caring for:

"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)

“ I'm unsure if carer harm was the 'right' word, it might even be considered offensive to use in instances where the person with dementia demonstrates responsive behaviours such as agitation and aggression towards a carer. ”

Dementia Focus Group Participant



Some focus group participants also suggested that they were seeing increases in instances of carer harm, particularly since the pandemic:

“ It's become quite common generally and certainly with the young people with autism. They obviously have you know... it is something we see more commonly at that level of agitation in themselves that can get taken out on the family, especially when they are not coping with other environments like school etc. Or when someone is trying to put limits on them that they don't you know understand or they find difficult to accept. ”

Autism Focus Group Participant

"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)

Another professional reflected on the increased presentation of carer harm and physical aggression or violence towards family carers,

"We are seeing an increase in that physical violence towards the carer essentially, pushing, shoving, hitting, biting would be some of the things we are being told about. And that kind of shouting, screaming, and then some of it is kind of that ongoing putting people down consistently and telling them they are no good or you are useless and things like that".

(Autism Focus Group Participant)



Stigma, Shame and Guilt

Family carers spoke emotionally during interviews about the shame and perceived stigma they experienced when disclosing their experiences of carer harm. For some family carer participants, it was the first time that they had spoken in any depth about the harm they had experienced. Many also expressed the guilt they felt talking about this and the conflicting emotions that they experienced around disclosure:

"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)

"And as well as that you don't talk, I mean I've told my sister and you told you people...because you don't want to admit I mean even to myself that my child was really hurting me, it's just unbelievable."

(Paula, Autism Carer)

Focus group participants also highlighted a general lack of awareness from family carers as to what is and is not acceptable behaviour. Whether due to a lack of awareness or due to stigma and shame, carers do not report or speak easily about the harm they experience in undertaking their caring role.

“ But it's all those feelings of guilt in saying I want to be able to have this child in my home I feel a failure as a parent not knowing what to do, how to do this. I feel guilty if I start moving towards that decision that I no longer can manage you know, and my child or the person I care for and I need to make the decision to try and find alternative living arrangements for them, that is huge on families. ”

FCI Focus Group Participant

“ 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, but can I say this to you. They are always apologising that they are talking to me. My response is always you know that you are human too, of course, you are going to feel you know, you never ever have to apologise for expressing your emotion. But just in one that 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

Autism carers discussed the fear that many family carers have around disclosing that they are experiencing carer harm in case it ends up with other children being taken into care or their child with a disability going to residential care or foster care:



Fear, you know, because, like I said to you, I mean the first thing that was said to – residential care, you know what I mean, foster care, you know. There was another time when A was 18, was it, yeah, when he just finished school, and he was in between, now again that was a huge, huge thing, getting him resources for a day service and respite, again residential care was the only option that was put on the table for me and again I had to say, he's happy at home, I'm happy to care for him and love having him, he is my son, you know what I mean.



Katrina, Autism Carer

Professionals reported that frequently a 'crisis' situation led to the need to disclose:

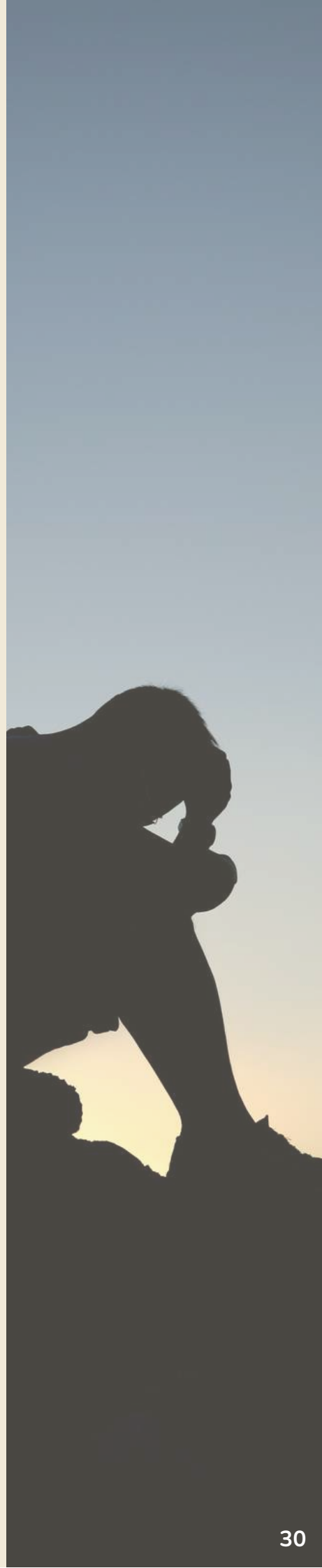
"It's only sometimes when that crisis happens somebody ends up in hospital, the public health nurse gets in the door and it's oh god what's going on here. A lot of families have been managing and they are also so ashamed of the violence in particular. They don't want people to know they are really worried that you know what would be the result that they will get hit harder. Or the person will be taken away, they will be locked up. I think that's the worry for us we are seeing people being criminalised because of disability because there isn't a response in the community".

(Autism Focus Group Participant)

Another professional reflected on the guilt family carers often experience about their inability to protect other siblings:

"The social worker who feels absolutely useless because we have nothing to offer them...then it's this feeling of failure that they are failing their other children because they can't protect their other children. So not only can they not protect themselves, but they can't protect the younger siblings, then there's also this overwhelming feeling of guilt".

(Autism Focus Group Participant)



A family carer spoke about their fear related to how others such as extended family or friends would perceive them opening up about their experiences of carer harm and for them, what was essentially domestic violence in the family home:

"The impact that the aggression of our child has on the family, I know it's not intentional obviously and D, poor D like would be devastated as well after D has a meltdown but you know we are talking about domestic violence. This is domestic violence in the home, no other way about it. And the child is not to blame obviously, I don't blame D for it but even though he's not to blame the effects are the same. They are exactly the same, I'm just so worried about my little daughter that's what worries me the most. And I don't think that part is understood, we are talking about domestic violence here, you know, something should be done about it".

(Lana, Autism Carer)

One focus group participant felt that professionals working in the area of dementia may unintentionally stigmatize dementia in the narrative they use when engaging with clients and families:

"I guess just around the stigma piece and in a way going back to the stigma of the broad dementia. The lack of clarity at diagnosis and giving it weight and giving it you know the clout that it needs and that's not loosely kind of 'Oh it's a bit of memory loss, it's-' you know. I think that diminishes what actually the role is then for the carer in a way because it's not as maybe officious. I know how that happens I know how I even discuss it myself we keep it all very function focused I guess here. But I think it's all that stigma that we just have in us, that then just means that the carer probably can't identify what is carer harm or emotional distress or is it the relationship change or is it the dementia or carer role. I think everything is so misconstrued like and nothing is clear".

(Dementia Focus Group Participant)

A FCI focus group participant reflected on the guilt and significant emotional impact of the disclosure process:

“ 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 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



Another professional expressed caution and concern however about the disclosure process and subsequent responses within the context of training:

"So, there's a lot of guilt there's a lot of burden of guilt, I think, on carers as well, and it's really important that that's recognised. Because sometimes what I'm hearing from people is the response of the services is train the parents. And so this burden of responsibility that is put on the parent's shoulders in terms of 'Well, now, you've got the training' you know. You should be able to deal with this' and if it happens well, 'did you put the training in into action?'... you know that kind of- I think that's a piece that's really, really important to take into account is the wellbeing of the carer will impact greatly on their ability to respond in an appropriate way to the behaviours of concern.'

(FCI Senior Manager)

An autism family carer talked about how difficult it was to make the decision to disclose the harm she was experiencing and the frustration she felt about the lack of an immediate response:

"It was our autism liaison nurse at the time, yeah, and she's since retired, but I do remember her not returning my phone calls, not replying to my emails".

(Katrina, Autism Carer)

For autism family carers, in some cases feelings of guilt were further compounded by the attitudes and lack of response by professionals and service providers,

"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

"Disability Managers and they would have all taken that kind of, almost a tactic, to kind of make a little remark that I felt was kind of putting guilt on me, you know, or putting it back on me or would have maybe made me feel like somebody is trying to just put me down here a little bit, do you know what I mean. And I think that's really damaging, I really think and there's a lot of people I know that don't go to meetings or arrange meetings because of that, because they've done it before and they came out feeling really bad about themselves, do you know.

Katrina, Autism Carer

Types of Carer Harm

All of the narrative interview participants spoke at length about their lived experience of carer harm by the child or adult they cared for with a wide range of types of harm experienced including shouting, screaming, damage and destruction of personal possessions or the family home and significant levels of physical violence as well as the knock-on emotional and psychological distress. Family carers also reflected on the impact on their own health and wellbeing as well as the impact on siblings (autism carers) and other family members (dementia carers).

Types of Harm Experienced by Autism Carers

Family carers spoke about the uniqueness of each autistic child, their family history, and traumas (some had experienced the loss of the other parent through death, divorce, or illness) but also the nature of their disability, how it manifests itself and the supports needed. The autism carers cared for children and adults who ranged from having autism with mental health difficulties but no learning difficulties to profound autism with profound intellectual disabilities. Two of the children being cared for were non-verbal with one also being partially sighted. Another had a rare genetic disorder and all children and adults being cared for had multidimensional and complex care needs.

Many of the autism family carers described living with the threat of harm on a daily basis, they never knew when a situation would deteriorate and they would experience assault or other types of harm for example, aggression and physical violence, psychological or emotional abuse and no sleep.

"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 every, 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 Carer)

"We have been into situations where we either grab him and take him away and take whatever he gives you physically or verbally. Like he was in the kitchen once and the knives were the closet things so his dad just grabbed him and I stood in front to cover the knives so I got a beating and my husband got a beating with his arms but he did not hurt himself. At that point that was the most important thing. Like I mentioned he has been throwing things while we are driving, and that is very, very dangerous".

(Valerie, Autism Carer).

"I turned my back, C ran after me and fired me down the stairs. I landed halfway down the stairs and C kicked me into the private part, C kicked me, stood on my head jumped, stood on my head with her foot, with a boot she had on. And then continued to kick me, I felt like as if I was paralysed. And I was stunned at the fact that my own child at twelve years of age would want to physically hurt me so much".

(Noleen, Autism Carer)



Noleen also spoke of her embarrassment when disclosing the harm she was experiencing but she knew she had to speak out in order to get help:

"In the very beginning, I said Jesus I can't tell them that C kicked me in the private parts. Or I can't tell them that I go to bed and my bed is saturated and that I have to sleep down in the armchair. Sure, that's so embarrassing, that you don't tell those things. But eventually, you have to say no, you are doing this so you can get professional help".

(Noleen, Autism Carer)

Some family carers spoke of the self-injurious and harmful behaviours that their autistic child or adult inflicted on themselves, for example, banging their head or hitting or punching themselves:

"He will, he can hurt himself as well, he bites his hand, he can sometimes hit his head off, or he can hit his head off a wall or whatever if you put him under too much pressure'.

(Katrina, Autism Carer)

"When he was small he used to bang his head so bang his head against the wall, against the floor, he used to flop to the ground every time and bang his head with force on the ground. Bang it on the wall and he banged his head so many times that he actually has a hole in the forehead that never closed".

(Lana, Autism Carer)

Of the five autism family carers interviewed - the mothers identified themselves as the main target of harmful behaviour. In many instances, however, other family members were also targeted and harmed. Family carers spoke at length about the significant negative impact on other siblings. For most, there came a time when they could no longer live with threat when it put their other children at risk:

But at home yes, yes, his older brother was, his older brother would have been targeted and his father, myself...we have another child it's a little girl and she's nine now and D (autistic child) has targeted her and succeeded on two occasions. So I had to, I had to report myself to Tusla [Child and Family Agency] because I could not keep a safe environment for my child anymore.

Lana, Autism Carer

Of the five autism family carers interviewed - the mothers identified themselves as the main target of harmful behaviour.



Lana spoke of the trauma she experienced after one harmful incident where her eldest son who was aged 11 had to physically restrain his autistic brother in order to protect his mother and the heartbreak and anguish this situation had caused her:

"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'll 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 Carer)

Carers also spoke about the need as a family to put in place plans and safeguards in order to protect themselves from serious physical harm on occasion:


"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 Carer)

For some carers, the carer harm they and their children were experiencing was life-threatening in nature- this was the case for Noleen and her younger son:

"C knocked me to the ground, had a knife in her hand and put it up to Y [younger siblings] throat.... C was choking [sibling] at the same time ... P [sibling's] eyes were closing because I could see it, I had to make a decision I had to go for her just to save the younger child. And I ran towards C, C kicked P [sibling]...I said here you haven't time to cry, get out through the window. I opened the window and the child got out through the window. C bashed me into the window. I didn't care, I didn't even worry about the pain".

(Noleen, Autism Carer)



Autism carers provided harrowing accounts of the types of carer harm experienced not only by them, but also siblings in the family homes. As parents and carers, they faced an impossible task of trying to balance care for their autistic child while also ensuring the safety and protection of themselves and their other children.

Types of Harm Experienced by Dementia Carers

Family carers spoke about the type of dementia their parent or spouse was diagnosed with but also some of their other underlying physical and mental health needs which impacted on the type of care they required. They also provided useful insights into the extended family context, past and current family dynamics and the intersections between these and the harmful behaviours they were experiencing.

The carer harm experienced by the dementia carers took the form of verbal outbursts, verbal abuse, aggravation, aggression and similar to the autism carers, lack of sleep. Dementia is a condition that covers a wide spectrum of symptoms which advance gradually. The people living with dementia who were being cared for had a variety of types of dementia. In two cases, they also had chronic alcohol misuse problems with one having also suffered a stroke and the other had Type 1 Diabetes. In another case, the PLWD had long-standing mental health issues which added further complexity and challenges for the family carer.

"I have to stay awake until she goes to bed at night because I have to give her pills to go to bed and give her an injection, and obviously I have to make sure she doesn't turn on or off anything that is dangerous. So, I literally, I could be up from 5am and she doesn't go to bed till at least midnight. 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 monitors 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)

"He would get, like... So the stroke affected his right side but he still had strength in that arm but he, you know, he's 81 now so when he came home he was just about to turn 80 but he had unbelievable physical strength in his upper, you know, so his legs, his arms, everything would be flying. He'd be very foul-mouthed, you know, very, like "fuckin leave me alone", you know, and like really, you know".

(Mairead, Dementia Carer)



"Verbally abusive, hitting out that kind of things...most of it was due to frustration".

(Oonagh, Dementia Carer)

Similar to the experiences of the autism family carers, sometimes harmful behaviours were targeted at other family members such as grandchildren as in Jennifer's case or there was the risk of harm to members of the general public as in Oonagh's case.

"So the problem was that mam was getting very aggressive, especially with the children and she loves them don't get me wrong but she's not able for the noise. And the attention, Mam craves attention, so all my attention was given to them and obviously the noise in the house changed. Everything obviously has changed, craziness with two other children So she got very aggravated. She doesn't mean it but like sometimes she would push him out of the way or shout and scream at them".

(Jennifer, Dementia Carer)

"While she was waiting for an appointment [for a memory assessment], things spiraled out of control...I think it was a kind of psychotic episode where she started threatening us with knives and she was taking the knives with her in the car when she was going out ..."

(Oonagh, Dementia Carer)

Family carers reported struggling to know how to manage presenting behaviours and for some, the professional advice given was not always seen as helpful or practical or the necessary advice simply was not provided.

"There are two sides to mammy, so one battle is the alcohol at night time- she believes she needs a drink to relax her to fall asleep, which is obviously not, she has sleep medication but she believes that. So that's one reason why she gets so aggravated. So if I don't give her enough alcohol she would come screaming, blinding, she could throw things at me, and I've been trying to find that balance over the last two years of letting her have some alcohol because with the dementia clinic, they say try to get her into a rehab but she refuses to go. They said 'Look, there's nothing you can do, just let her have it'. They literally said that to me the last time."

(Jennifer, Dementia Carer)

"The Community Mental Health Team immediately put her on anti-psychotics, but we didn't get any tips on how we could deal with her behaviour".

(Oonagh, Dementia Carer)

Types of Carer Harm-Professional Perspectives

Focus Group participants also spoke about many different types of behaviours which they had encountered in their work which they understood to be carer harm. In relation to autistic children or adults, this included physical aggression, emotional toll, destroying the house, a constant sense of threat, physical assaults as well as the impact on the family carers' mental health.

"The other thing I suppose I would experience when it comes to behaviours that challenge with families is the guilt. The guilt of letting their own child down, or young adult or adult down who has special needs. Guilt within not being able to care the way they would like for their other children"

(FCI Focus Group Participant)

“ It's this constant sense of threat, living with that toxic- we talk about it for children toxic stress, but these parents and children living in homes where a person doesn't have a lot of insight into their behaviour because of a diagnosis of autism they are living under constant threat...You see the consequence of years of minding you know people who have autism. You see it where there's stress and anxiety, depression, suicidal ideation, and you see it on the other end where they are embarrassed that they feel this way they feel that they should be equipped to care for someone with that level of need. But there's no book, no instructions. So, it's multifaceted I think, I think I've seen it in all areas of social work that I've worked in.

Autism Focus Group Participant



Autism professionals also spoke about the significant impact on other family members including neglect of other children in the family or breakdown of the whole family unit.

"I spent years (working) in mental health where we get a lot of parents of children with autism. So, a lot of the stuff that they would want to talk about is the impact that it had on other children or the impact it had on them".

(Autism Focus Group Participant)

"...So, in those conversations it's quite normal that we'll hear about, they'll talk about ten-year-olds you know 'Well Mary is okay she just minds herself. She just goes to her room, and she avoids things, and she's not a bother'. But what happens is you realise that Mary is rearing herself, because Mam and Dad don't have the time. And you also find that, well in the out of hours [social work service] that a lot of these families are single-parent families. And it's often the Mam that takes responsibility or they are separated families where maybe Mam and Dad are so exhausted that neither one of them want to take primary responsibility for the child. So they are battling it to each other. The child is going from one home to another, then they end up in care so maybe they will be taken into a residential unit.'

(Autism Focus Group Participant)

The educators interviewed also spoke about families struggling to manage, the impact on siblings, and what supports might be helpful, for example, play therapy.

"I see this particularly with a couple of families in the school that siblings are really struggling. And the parents, they don't want to disclose it to you either. Because again it's kind of an indication of they feel that they're not coping themselves at home. You know and number two, another child then is impacted by, of course, they're impacted by the behaviour of the child. Because they're exposed to it all the time. And if they have not experienced any other behaviour that's normalised for them, isn't it? So, they nearly have to learn, so play therapy would be essential for those children, you know to help them, you know normalise kind of interactions and to put it into perspective as they get older. But even at a young age, oh yeah essential".

(Autism Educators Interview)

Dementia professionals also reported that family members frequently experienced psychological, emotional, and physical harm when they took on the role of a carer for a PLWD.

"It is a really frequent all across all our groups because we would have twenty people at a time, and over the last three years it's a common recurring theme of having to deal with".

(Dementia Focus Group Participant)

"I suppose harm caused by not just the symptoms which include physical and verbal aggression and all of the non-cognitive symptoms but also being forced to undertake care is really harmful mentally for family members".

(Dementia Focus Group Participant)

This was reflected by screening tools used by professionals.

"I measure depression I measure anxiety symptoms and I measure their burden scale and I do all that within the family carer training group. It's always through the roof and I just think that that's another element of harm".

(Dementia Focus Group Participant)

Expectations, Responses and Systems that Harm

Family carers and professionals reported that family carers and the person they are caring for can also experience harm as a result of unrealistic expectations, pressures and in how the education and the broader health and social care systems treat them.

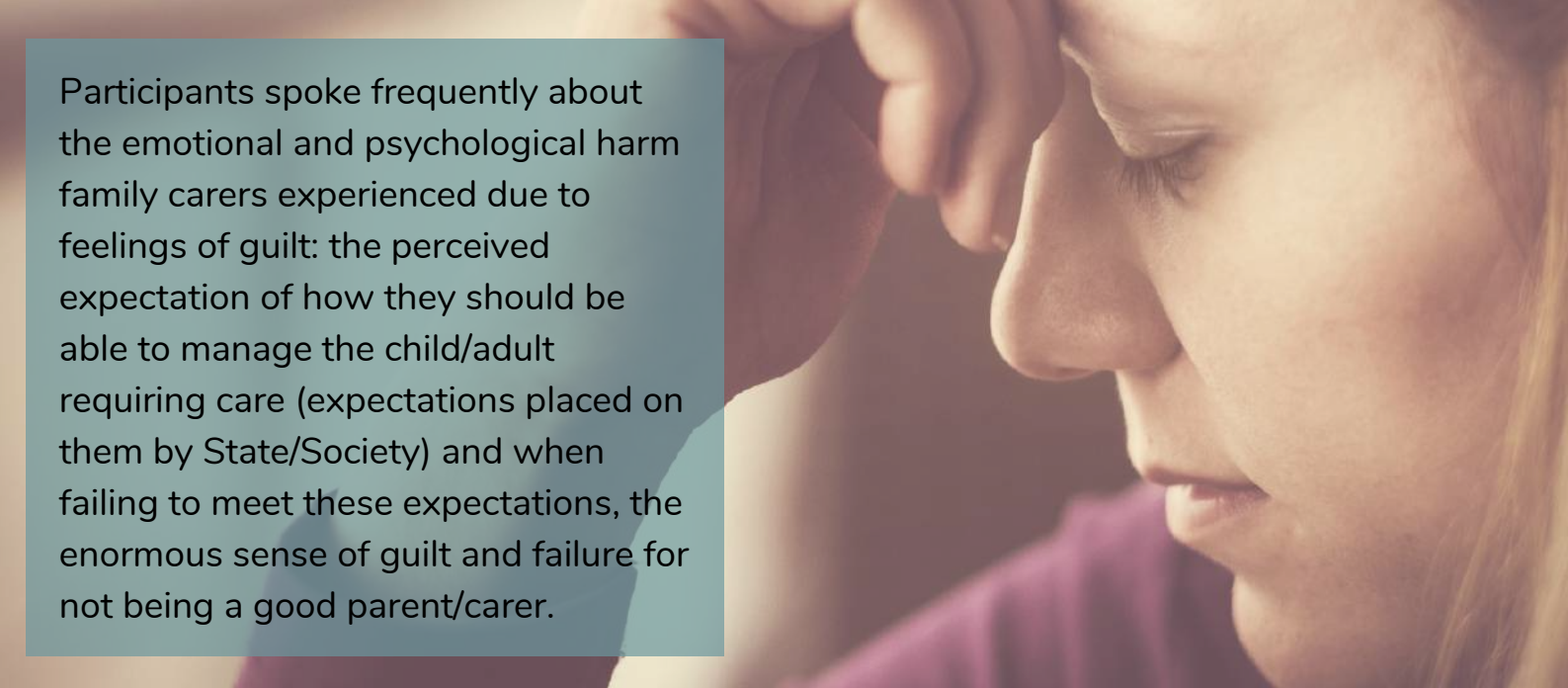
Family carers commented on the harm caused or exacerbated due to lack of services and supports and in the way some healthcare professionals engaged with them. Professionals also spoke at length about this as well as the unrealistic and unhelpful societal expectations which were placed on family carers which were considered a contributory factor in the harm experienced.



This perception, as I said, that's just 'You're getting Carer's Allowance, so you've signed your life away'. And exactly, what does it mean to be a family carer? And you know, 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





Participants spoke frequently about the emotional and psychological harm family carers experienced due to feelings of guilt: the perceived expectation of how they should be able to manage the child/adult requiring care (expectations placed on them by State/Society) and when failing to meet these expectations, the enormous sense of guilt and failure for not being a good parent/carer.

"This is the harm of the system, that, you know what I mean, the harm that it causes.... And I think the State really takes advantage of that. And by doing that people like me get run into the ground over years and years of it".

(Katrina, Autism Carer)

Professionals also reiterated that there is a general expectation that the whole family will provide the necessary care, including other children in the family acting as young 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. It's so wrong".

(Autism Focus Group Participant)

There was also an expectation that family carers would cope with huge amounts of care alone in situations where professional carers would not be required to.

Katrina discussed how she was expected to care for and support two adults with multiple disabilities alone. Katrina explained that her son has "Moderate autism and moderate intellectual disability but again he's a big chap, not quite as big as his brother J but he's still growing, he's six foot two. I mean he has very functional language.... A would be very dependent on me across all of A is incontinent so would need, you know, I suppose very intimate care needs around incontinence... would also need full support around washing, shaving, dressing, you know, all those kind of, now J can assist himself, you know, A can maybe put his arms through his t-shirt and pull it down".

Lana also explained how her son has two-to-one carer support in every support/service setting. He goes to school by himself on a bus with two bus escorts, but at home, his parents are expected to manage despite one of the parents having a neurological condition. Recently Lana and her husband have made the difficult decision to seek residential care for their son as they can no longer cope.

"So that I mean that combined with my husband illness it's impossible to manage D at home, so then we, well our hearts were broken when we done this but we had to go to the next step and ask for D to go into residential care. Because we can't manage him at home. We tried our best for seventeen years and we can't do it, but then eventually you know that was a, that was approved and D had a residential placement".

Lana went on to reflect on how it didn't make sense that schools demand and are provided with two-to-one staffing however family carers are not offered the same level of support.

If a school that is highly skilled and they have two-to-one adult and they cannot deal with it, how does the system, the government or the HSE or whoever it is how can they expect that these children are kept at home, being cared for by parents who are usually you know getting old because these are teenagers.

Lana, Autism Carer



In situations where there is an immediate danger of harm to the family carer and their children, the parents' only solution was to call the Gardaí (the police). In this situation, the Gardaí can seek a 'Section 12' Order and then bring the child to the Accident and Emergency Department in the local hospital. Noleen explained the process:

"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)

Noleen also reflected on her interactions with the social workers in Tusla, the Child and Family Agency when they visited her in hospital while recovering from fractures as a result of an assault by her autistic child. Noleen spoke of her fear and shock when the proposed response was to threaten to take Noleen's younger child into foster care and to leave Noleen to care for her daughter who was exhibiting harmful behaviours in the family home.

"The Monday morning social workers and Tusla came down and explained it to us, that there was nothing that can be done. I said even though C tried to choke [sibling name] to an extent where his eyes were blood shot. And then they turned around and said well, we didn't know that but I said well it's in the Garda report from the weekend and they said oh we'll have to look into that. And that's a whole different ballgame that we can't have sibling in this house where C is. So, they tried to twist it in a whole different way, that they were going to look at taking P [sibling] out of the house. My whole stomach just turned, and it was like as if it was a threat. If you don't take C back, because Section 12 is only 72 hours I think...If you don't take C back, we will look to take P [sibling] out of the house and you continue to mind C but there will be no problem getting P [sibling] minded".

(Noleen, Autism Carer)

Some of the family carers reported that they were 'forced' to abandon their autistic child/adult in order to access the supports their autistic child needed, but also to keep themselves and their other children safe.

"And then what is happening is that families are forced to abandon their children in hospital because that is the only way that you can get residential care. I'm not prepared to do that, I know that that will get me somewhere but I'm not prepared to do that".

(Lana, Autism Carer)

"We didn't want this [to put 12-year-old child into residential care] and if we had more respite, we might have been able to, I don't know. Maybe we would have been able to contain the situation, but you know, as I said we didn't want this. I still don't want this but it's the safest situation at the moment and we do hope to have more access when he gets settled in ... I haven't given up on finding something to help him you know".

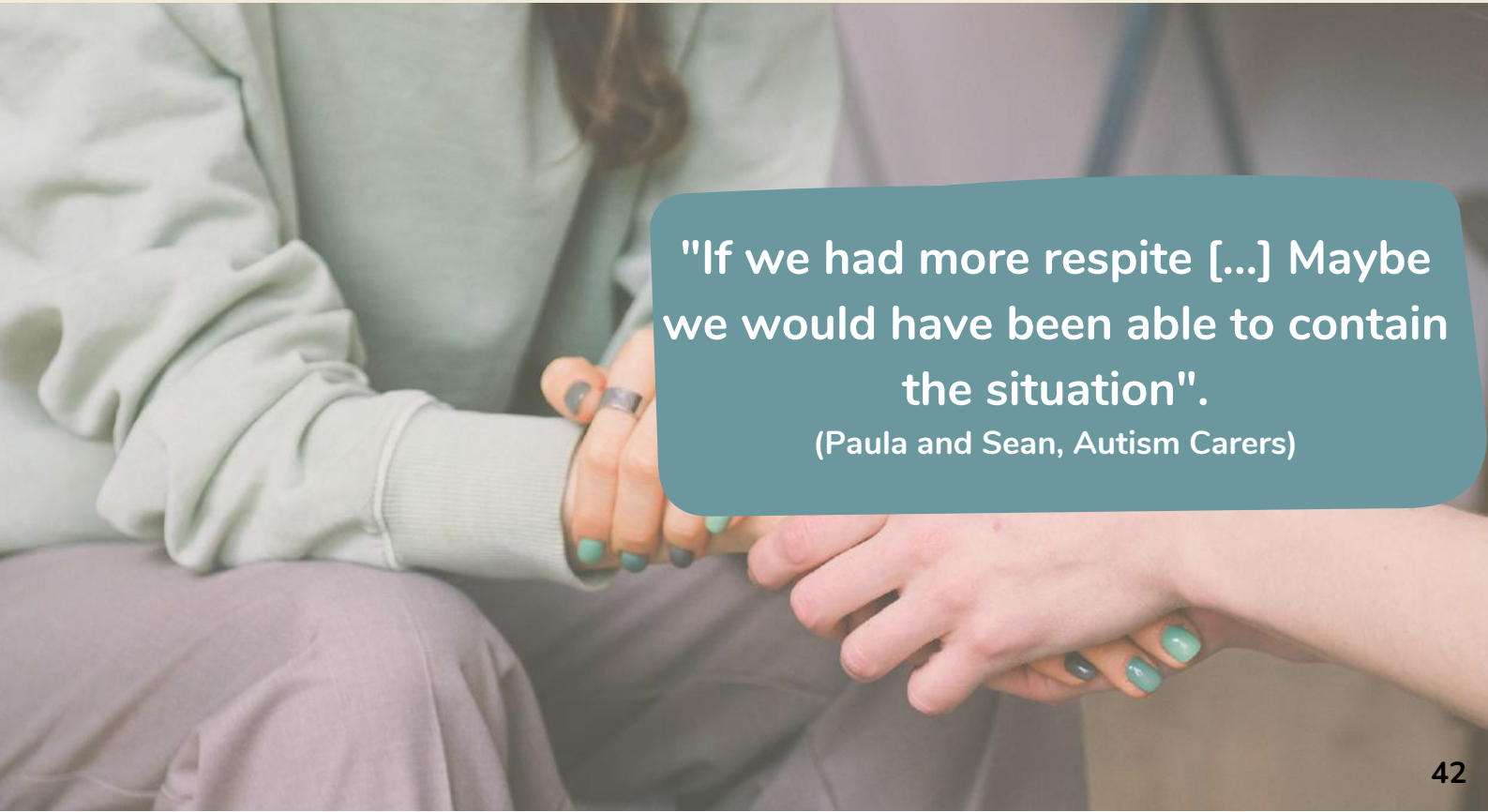
(Paula and Sean, Autism Carers)

It was only when family carers 'gave up' their autistic child to the State, that the system took responsibility for providing care and provided funding as Paula and Sean explain when they took the difficult decision to refuse to take their child home from the hospital:

"E's in the hotel, from Monday to Friday and then Friday after school he goes to [Residential Unit Name], he's the only boy in the house there. And then on Monday morning, they have recruited a person in charge for the house, but they don't have enough staff, so they have support staff from an agency Home Instead so that's who is minding E".

(Paula and Sean, Autism Carers)

Several autism carers reported how after months and often years of trying to advocate strongly for the professional help and support that their child required to no avail, as a last resort, they contacted their local political representative or the media.



"If we had more respite [...] Maybe we would have been able to contain the situation".

(Paula and Sean, Autism Carers)

Katrina explained about her experience of seeking some extra support after a crisis situation to help her care for her two autistic sons.

"I remember one Disability Manager saying to me, well, you know, we only helped you out...you know, we couldn't possibly continue to give you the level of service, you know, we have other people to give the service to. Now that was, as I said, when I had one day off, you could say, a month...I went on the Joe Duffy Show to say that they were- now 'I've been told that these services were about to be taken away'. And there was kind of uproar, there was a lot of people kind of ringing in, supporting us, the general public, they're very good. The Irish Independent contacted me, they did a piece on it and all of a sudden, I got an email to say, you know, that the services, that they would keep them for another year".
(Katrina, Autism Carer)

While this worked in the short term, Katrina has lost this support now and has to manage to care for her two adult autistic children alone.

Lana also spoke about how she tried to engage with the Ombudsman for Children, the Minister for Disabilities and eventually her solicitor in an attempt to secure a school place for her son.

"Yeah, but that's what you get all the time, it's passing the ball, 'It's not me it's not me, it's not me'. Like I went to the Ombudsman when D was expelled but because the school had initiated court proceedings the Ombudsman couldn't get involved. So like, so nobody done anything...I mean I drove to the last meeting with the HSE and Minister Rabbitte was with me at that meeting. The HSE are not threatened by anybody, they don't care. You know, if it's the Minister, they just don't care. Even if there's, now I have a solicitor on the case, they don't care they are ignoring my solicitor as well".
(Lana, Autism Carer)



2. Protecting Family Carers from Carer Harm

Theme two helps us to answer our second research question which focused on exploring and understanding how professionals and service providers can better support and protect family carers who are experiencing carer harm. This section explores themes related to the antecedents, which are the significant events or experiences that influence and shape carer harm experiences. Findings help to shed light on protective factors and considerations. Five primary antecedents were identified namely:

- 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

Diagnosis as a Critical Juncture

Diagnosis was identified as an important first step by family carers. Many described the experience of living and managing through a period of not understanding what was happening to the child /adult whether that was developmental delays, changes in their behaviour, or ability to function.

Professionals reported that delayed diagnosis was a missed opportunity for family carers to fully understand the condition and often had a knock-on impact on engagement and behaviour patterns already having been established between family carers and the child/person they were caring for. For many of the family carers finding the answer to what was 'wrong' with their child/parent/relative or why they were acting differently was a long process.

Some family carers of autistic children reflected that their initial concerns about their child's behaviours were minimised or dismissed by professionals such as their GP or PHN and for others, long waiting lists meant they had to pay privately in order to get an initial diagnosis.

"We just knew there was something not right so I kind of said it loads of times to the public health nurse and I was being dismissed, you know like 'Oh you know mothers are always comparing with siblings...'. And I told her I said 'Well, look even if I don't compare with sibling it's not right for a ten-month-old not having interaction at all'.... I'm from X Country originally so I had the option to get a neurologist in X Country so when D was ten months I travelled there. Only five minutes with the doctor he said 'Yes you are right, there's something here'".

(Lana, Autism Carer)



Parents observed behaviours that concerned them when their children were still toddlers, as Noleen explains – "I knew that there was something not right with C when she was about two or three".

Behaviours that concerned Noleen included her daughter's reaction to food, the smell of certain foods triggering a tantrum or behaviours such as standing and walking on the table. However, these observations were trivialised when Noleen tried to explain them to others:

"These are things that are always very difficult for me to explain it to professionals and other members of my family. This is why it was so difficult on us because nobody else saw it".

(Noleen, Autism Carer)

Noleen reported that it took another five years for her daughter to be assessed for autism, and this was only possible as she got help paying for a private assessment from the primary school her child was attending:

"And I can't get a diagnosis, I had to fight, fight, fight. And the diagnosis I got was through the school and they actually helped me pay for it, through a paediatric consultant that specialises in autism. But that took five years, I was on the waiting list because seemingly the school is given a certain amount of money to help families. And I suppose they only pick out the worst of the worst".

(Noleen, Autism Carer)

Delays in receiving a diagnosis had consequences for the children. Often, they miss out on early intervention, as Valerie recounted:

"B was on a waiting list for about four and a half / five years. It's a waiting list for a waiting list. Whenever B's time comes to be seen by someone, they change. So it's another waiting list and another waiting list, B has completely missed out the primary care and early intervention. Because when B was diagnosed, he was post-op and many consultants, and many psychologists thought B's just behaving the way B's behaving because of what B has been through. Therefore, B completely fell through the cracks on that regard".

(Valerie, Autism Carer)

While diagnosis provided answers for some parents, it also confirmed with certainty that their child was autistic, and for some, this caused conflicting emotions, as Valerie describes:

"Yeah, I guess for me I have had my cries, I have had my anger and everything but at the moment I accept, the hardest thing was to accept his diagnosis. That took me five years, once I accepted his diagnosis it got better. And then once I accepted that there's nothing out there that can help me, so now I'm fighting (laughing) to bring attention to this".

(Valerie, Autism Carer)



Focus group participants also reflected on the difficulty and importance of getting a diagnosis for adults in a timely manner.



In adult services we are seeing so many who have had no diagnosis they have slipped through all the gaps that there are, all the cracks. And so we are coming across them in their twenties, thirties, forties, fifties, sixties, and no contact with services. We are going begging services for help; they are saying but you haven't got a diagnosis... And you will get a diagnosis when they are criminalised [in the criminal justice system]. Because they will be entitled to an assessment for their defense. But that's nearly becoming a first step for some of the referrals to us is that they are in the criminal process and they are going to get a diagnosis, which is horrendous.

And it's not what families want, even if they have been assaulted, it's not what they want. They want help.

Autism Focus Group Participant



Dementia carers and professionals also spoke of the issue of diagnosis and reflected on this process. As with family carers of autistic children/adults, family carers described noting changes in their spouses/parents functioning for some time, before they were aware of the cause of these changes.

Jennifer describes how her mother who experienced a brain injury in her 50s, was eventually diagnosed with dementia in her 60s when her daughter took over her care:

"Because mam suffers with her mental health, she suffers with memory and anxiety. We got her diagnosed and she does have dementia they said she probably has dementia for years with the alcohol masking it. Because they had to do all these scans, when she was with her partner, he never did any of these. So, when I became a full-time carer again, I re-evaluated all her illnesses and her doctors and all these things. So they formally diagnosed her with dementia".

(Jennifer, Dementia Carer)

For Mairead, they never received a diagnosis as to what type of dementia her father had, "Like he has, well he definitely has vascular because he had a stroke so, but there was something there prior to that as well, so what the actual diagnosis is, I can't honestly say..."

(Mairead, Dementia Carer)

The difficulty in getting a timely diagnosis of dementia was also highlighted by professionals.

"For many families, they have been living with this for many years because it takes so long to get a diagnosis. So, they are walking into the memory clinic and coming out the same person, but for the carer, there's often relief around the diagnosis... but for the person, the family member hearing 'Okay so this is what we are dealing with now. This is dementia, this is why you know I have noticed all these changes in the last couple of years' sometimes that can be a like a moment of relief. You know, knowing these are the practical steps that we can actually do, these are things that will help".

(Dementia Focus Group Participant)



Delays in getting a specific dementia diagnosis meant that family carers of people living with dementia, like those supporting autistic children or adults, had to manage changes in personality and behaviour without any guidance or proper understanding. This contributed to conflict and violence as observed by this participant:

"And someone who could have been a very gentle kind person in the early stages their personality changes and violence can come into that. So yeah, again I suppose that's about educating the person maybe to expect those things, but actually, sometimes the diagnosis hasn't been made when the violence begins you know".

(FCI Focus Group Participant)

The way a diagnosis of dementia is communicated was also seen to have a negative impact on relationships between the PLWD and spouses/partners/ family members. Some professionals pointed to how communicating the diagnosis to a spouse/partner or another family member without telling the person themselves, or in a way, they were unable to fully appreciate what the diagnosis means, 'sets the scene all wrong' from the start, as these participants discussed:

"We would often say that the diagnosis in particular we are meeting a good few that aren't, even though on paper it's said they were told but actually they don't feel they have been told. And that causes a huge impact then on a family member thinking that they have been told. They themselves not actually being told, and it sets the scene all wrong. It means now that somebody else knows something and so there's a paranoia maybe about that".

(Dementia Focus Group Participant)

"It's about relationships and communication most of the time. That's really what it boils down to a lot for me. And I suppose when people are there getting a diagnosis and I'm sure people are told they have dementia, but it's not heard. It's just not heard. And then it does change the relationship because as [Name] said that suspicion is there".

(Dementia Focus Group Participant)

Professionals reflected that this damaged trust between the PLWD, their family and professionals and can cause strain on relationships and lead to conflict.

"I notice a lot, lately, maybe more often but paranoia really with partners/wives/husbands in particular the blaming is huge. For stealing or taking money, now maybe it's not an awful lot but definitely in the last while there's been a lot about if they can't find their keys or wallet the suspicion is that their wife has taken it away. And it's again this blaming about driving and money, those two things tend to come up a bit".

(Dementia Focus Group Participant)

Without knowledge and understanding of their diagnosis, the PLWD feels excluded from decision-making, the family carer can be blamed for changes in their lives such as decisions related to the cessation of driving, thus exposing the family carer to reprisal.



I think that yeah the paranoia and the driving we would always recommend that you know, someone, professional speaks to them really properly about the diagnosis separate or speaks to them properly about that they cannot drive. It's not their wife making the decision up, it's the doctor or someone has really went through it and given that time they have more buy-into that if that's the case we find.



Dementia Focus Group Participant

Early Intervention

Findings suggest that early intervention and a continuum of supports are the foundation for positive relationships and family carer well-being. However, participants reported that a diagnosis of autism or dementia did not necessarily bring with it supports and services for the autistic child/ adult or the PLWD; nor support for the family carer.

Autism participants reported that early interventions (for example, early appropriate education) were critical to building a foundation for the autistic child's future life chances. One autism educator commented that it gave the children the skills necessary for social inclusion and independence:

"It's like a young child who has issues with personal care, we work so hard to develop their independence and enable them to go to the toilet independently because we know that down the road that's just going to open so many doors to that child, they're not going to be wearing nappies when they're adults, they're going to have that independence and it's just going to be easier for them to go places and to do things and to join different groups. And that's a reality".

(Educator Interview Participant)

Another educator reflected that it provided parents with an understanding of autism, ways of communicating and strategies for managing responsive behaviour.

"So it's a learned behaviour really...So unless there's intervention and guidance for the parents at a very early stage, like a lot of speech and language therapists need to get in there at an early, at the early, early stage. Because by the time they're 6 and 7, it's nearly too late."

(Educator Interview Participant)

However, the requirement for a specific diagnosis in order to access services and support was often a significant barrier to early intervention, special education, services, and professional support.

"D couldn't attend any special class or in a school because he didn't have a diagnosis of autism. So back at that time if you only had a rare genetic diagnosis, you weren't getting anything. So, the autism nurses helped because... when D was about four or five, and D was going to a pre-school a mainstream pre-school with an SNA. But when we got the diagnosis of autism we transferred him to a special class in a mainstream, special preschool class specific for autism. Where they were totally, there was only five children, and they almost had one-to-one and what a difference, so we were delighted like I mean that sounds crazy but we were delighted with the autism diagnosis because that then opened the door a little bit for different stuff".

(Lana, Autism Carer)

Not being able to access early intervention such as autism-specific preschool and primary school classes can mean parents are left to manage their child at home in isolation as this interaction between educators outlines:

"And my heart goes out to them; possibly just stay at home...And they ring and they're desperate... Oh my god yeah, it's very hard. And you have to say no but we have only resources to you know manage so many".

(Educator Interview Participant)

Mainstream pre-school environments are not always appropriate, and the educators advised that this can escalate sensory issues and behaviour.

"So there could be 12 in class and one child, say 11 and one child with autism. But already for that little child with autism, it's just overwhelming, it's too much, they can't cope with all that...The stimuli, the sounds, the environment, the expectation that they're going to you know go along with this routine with everybody else, they just can't cope. So, a lot of them struggle in those environments ... often times they're asked to be taken out. And that sort of compounds a whole sense of failure for the parent, the child before they've even started...And I mean like it has to be, again I think embarrassing for parents to say well my child actually couldn't even, they couldn't take him or her in an early childhood setting".

(Educators Interview)

Some professionals reflected that challenges at the beginning of the autism journey can be very upsetting for parents, knocking their confidence, and resulting in the development of parenting styles that may not be suitable for managing their autistic child's emotions and feelings.

As with autism, there was limited provision of early intervention or services for the PLWD and support for the family carer, even when family members were experiencing psychological, emotional, and physical harm. Jennifer who has two young children and works outside the family home spoke about her situation when her mother who has dementia moved in with her due to her increasing care needs.



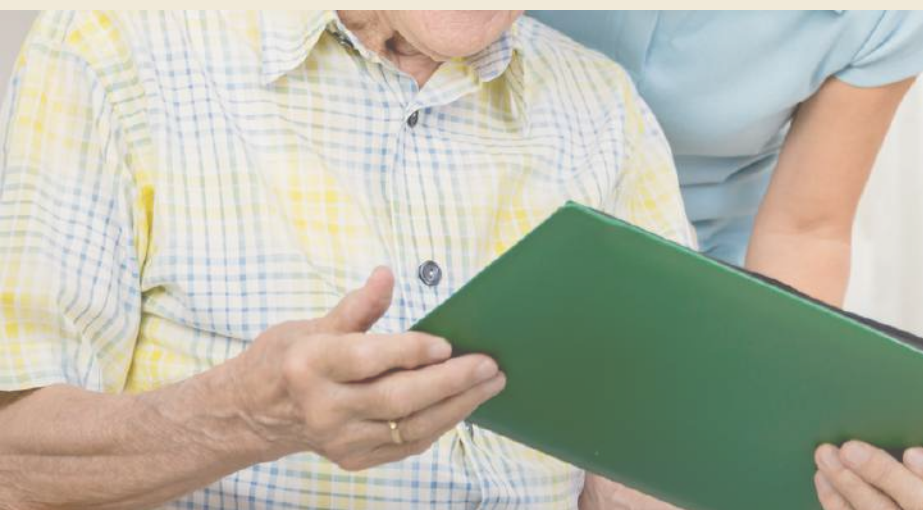
"She gets too heavy handed with me or the kids. And the hardest is the weekends because I'm here at home, obviously the weekends the kids are here and she (Mother) doesn't get enough attention at the weekends and because the kids are here all weekend that's when she's most aggravated.... she can throw things at you, she could, she is verbally very abusive that way, a lot of it is more tongue. I'm not going to say she doesn't always throw things around but she's more likely to pick up something and throw it at the door rather than me. She's frustrated and worked up and towards me, it's more, if I told you some of the things she'd say to me when she's in the height of these acts....It's so hard to, people say 'Oh look she didn't mean it it's water off a duck's back', but it's so hard for me to go to sleep at night after hearing those horrendous things said to me and everything you do and try to do because in the morning she doesn't remember you see. So, she's all happy and I'm like 'My God, the things you said to me last night' it's so hard to wipe them clear and start again".

(Jennifer, Dementia Carer)

When the PLWD exhibits responsive behaviours, the pathway to expert assessment, medication and follow-up was also not immediate. Dementia carers reflected on how opportunities are not taken by professionals to address issues at an earlier stage, for example having the PLWD assessed by the HSE Mental Health Services for Older Persons when agitation first becomes evident. Mairead recounted how she had to try and cope with her father's agitation and aggression for months.

"We never had a proper, proper review of his medication, you know, psychiatry in later life would prescribe, the nurse specialist might come back a few weeks later, you know, but it was, you know, there wasn't a proper, and look, I appreciate all of these services, community services are completely over-stretched and, you know, not providing the service I'm sure that they would like to be able to provide but we kind of felt his meds need to be reviewed properly in a medical setting".

(Mairead, Dementia Carer)



Focus group participants discussed how helpful information and education can be for family carers. By improving their understanding, it can empower them to better cope with presenting behaviours.

"But I really believe in that initial clarity explaining what it is, again like you said what the diagnosis is, what's the subtype and then it's educates you around what that means and what part of the brain. People are so enlightened when they get the slightest bit of, it's not even huge but it's very little education and if you can relate that to functioning and environment or perception you know whatever paranoia or suspicion and anything else, they are the best assessors ever.... And so if they get the diagnosis they'll come here but that could be six months later. So there needs to be real effort at that beginning and get everyone on, yeah equally on the same page; the pathways are I suppose when I talk about the diagnosis".

(Dementia Focus Group Participant)

Transitions and Responding to Changing Care Needs

Many participants also highlighted the need for awareness and increased supports at key transitional stages such as puberty (autism) and increasing or changing care needs (dementia).

Professionals recounted how the intensity of responsive or harmful behaviours can increase at times of transition for autistic children/adults; for example, puberty, transitioning from primary to post-primary school or moving from school to a support service/day centre. Autism participants identified puberty as a particularly challenging time. As for all children, hormonal changes at puberty can be a difficult, but for an autistic child, anxiety levels may increase and as this professional explains:

"When all the demands increase and increase on them, and you have puberty kicking in as well and the normal developmental stages where you kick back a bit at your parents and yet somebody is very black and white in their way of thinking and rigid. And finds it difficult to move beyond if there's been a conflict that's going to make all that much, much more difficult".

(Autism Focus Group Participant)

Other professionals also spoke of the transformation of autistic children on reaching puberty.

"You know puberty is difficult for the normally [typically] developing child, but for children with additional needs it can be explosive. And there is a correlation between, do you know with additional needs and psychological or even psychiatric issues when they reach puberty, you know... like a complete transformation in a child".

(Educator Interview Participant)

Increases in conflict at this time often resulted in carer harm as observed by this support worker:

"The thing that I'm seeing quite a lot of now is carer harm in around you know young adults and adolescents children with particularly autism or whatever when puberty hits my goodness really the house goes into chaos".

(FCI Focus Group Participant)

Family carers also spoke about the impact of puberty on the autistic person's behaviour and the resulting harm they experienced.

"[Puberty] changed, it changed E totally... Things that were a little bit bad got so much worse... Oh so much worse. So... because you know his life structure nothing changed but his behaviour changed dramatically so you'd nearly put it down to puberty".

(Paula and Sean, Autism Carers)



It's not the same to deal with a meltdown of a child who is five or six, seven or eight, but deal with a meltdown of a child who is thirteen or fourteen it's completely different. And even at home, so even though the episodes reduced in quantity, they were significantly increasing in intensity because you know when he was five if he punches a wall nothing will happen. Now at home, it's full of holes in the wall, because he punches them with such strength.... then what happened was when he was smaller it was self-injury behaviours, but as he was growing, he started to display targeted aggression as well...So you get a punch from a fourteen-year-old, fifteen-year-old and my god it hurts you know.

Lana, Autism Carer

”

While professionals were aware of the ‘explosive’ impact of puberty for some autistic children, they felt that “parents wouldn’t necessarily know about it” (Educator Interview Participant) and therefore they would not be prepared for these challenges.

The progressive nature of dementia also means that the PLWD will have different support and care needs at different stages of the disease. Some family carers and professionals highlighted that when family carers were required to provide more intimate care to the PLWD, they can be more at risk of harm. Mairead spoke of her father and how he gets very agitated when his 80-year-old wife and one of his adult children provide personal care:

"Full hoist...he was doubly incontinent, he was unable to feed himself...when he was leaving hospital, we were told he was going to get three calls a day, you know, there would have been two people, three times a day. In reality, what we got was two calls a day, morning and evening so we were then trying to fill in ourselves as a family at lunchtime so obviously, like if he’s incontinent, he needs to be changed, you know, so, and that’s a two-person job. He was very agitated during personal care so that was very challenging, you know".

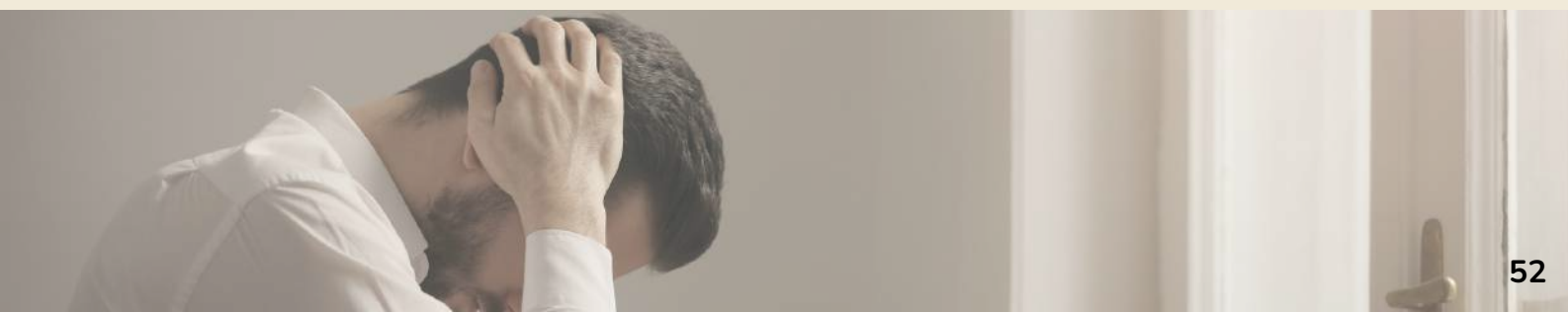
(Mairead, Dementia carer)

Professionals reported that family carers may also experience distress when the PLWD is going through a stage where they have a strong attachment to their partner and are constantly shadowing them.

“His wife feels completely stuck and she’s really distressed. He’s shadowing her but you know if she could just get a package which would include just somebody coming in and being with him, like accompanying him”.

(Dementia Focus Group Participant)

These situations create tension within relationships, heightening the risk of arguments, conflict, and harmful behaviours.



Navigating a Fragmented and Complex Health and Social Care System

Participants reported the challenges of navigating a fragmented and complicated health and social care system. The negative impacts on family carers and the person they were caring for when unable to access the appropriate, condition-specific services were repeatedly highlighted. Participants reported that 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 as observed by many of the participants.

“ It's currently under a bit of negotiation... There hasn't been like ultimately my understanding is it [autism] fits within Disability [services]... but disability you know is a broad area. So Primary Care fits into that and then the Children's Disability Network Teams and you know so primary care is obviously throughout life. But say for example in terms of the ASD [autism spectrum disorder] pathway specifically that is a national piece for progressing disabilities but that bit still hasn't been finalised. ”

Autism Focus Group Participant

“ 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



Some participants suggested that pressures such as staffing and resourcing within organisational systems and structures result in services taking a 'silo' mentality, imposing strict diagnostic categories for access, resulting in families living with the risk of harm as the autistic child/adult is not getting any professional input.

"We find that we would have a lot of people who like with dual diagnosis, intellectual disability and mental health, and then it's like oh no it's not, if they go to the hospital no they are linked with your service we won't admit them to the mental health service. And there's this back and forth, as opposed to working together you know 'How can we all support this person the best way possible?' and there's this kind of internal you know 'Who owns the person? Whose remit does it fall under?' And I think that starts with children essentially and moves it's way right through to adults".

(Autism Focus Group Participant)

"Nearly all the services are so under-resourced, like, we are just not staffed and resourced the way we should be at all [Child and Adolescent Mental Health Services (CAMHS)], any of us. And I think in fairness Disabilities probably are worse, you know from what I can see just seems to be particularly bad. But we are not well resourced either and our referral rates and the complexity and severity of what is coming in the door has increased exponentially going back to say the recession and you know from 2008/09, we lost staff at that time. Our referral rates have gone up, up, up, like hugely. And we have had no increase in staffing in that time and now COVID has just really backed it up. So, the eating disorders have become hugely problematic and emotional dysregulation, that would often be part of autism, that can fit into both of those areas. So, then we have to get tighter and tighter with our gatekeeping".

(Autism Focus Group Participant)

For some family carers, this left them struggling to figure out where their child with autism, who is now a teenager with significant anxiety, fits within the system, as explained by Paula and Sean when they brought their son to the Accident and Emergency Department of their local hospital. On a previous occasion, the hospital had prescribed diazepam to their son, to calm him, so his parents thought that his medication might be reviewed and that he might be admitted to the care of CAHMS.

"But that's not what happened because the consultant psychiatrist said 'No, it's not suitable for E to go to CAMHS' which is not fair because his medical diagnosis, the fact he has autism you know, they nearly- that precludes him from going to CAMHS. They are saying 'That's for kids with eating disorders and with neuro-typical kids'. And it is for neuro-typical kids but what happens, what do we do for a child like E. I mean we had a security guard [in the hospital]".

(Paula and Sean, Autism Carers)

Even where health and social care services are aware of the risk to the safety of family carers and other family members, they can take 'an arm's length' approach as Katrina describes:

"So, the support is now gone since before COVID. I don't, I don't- we don't have any support for A in the morning, even though, you know, there's- so A's bus comes at 10 o'clock in the morning to collect him to bring him to day service. So A doesn't leave until 11 o'clock because I have to give him so much time in the morning. Step in, step out, step in, step out, so that I can protect my own safety and I can protect his safety, you know because A can hurt himself as well, A bites his hand, can sometimes hit his head off, or he can hit his head off a wall or whatever if you put him under too much pressure. But the bus and the two staff, because A is two to one, he's a priority level 1, so he has two, two staff members with him, always, you know, if it's outside of the home. Any time he's not in my care, he has to have two people with him. If it's in the home or if it's in day service or if it's in respite. So the two staff members sit in the bus waiting for him because now it's not the staff's fault. The management in the service provider won't allow them to come into the house because of COVID. So, look it, I suppose, yeah, it's, most mornings I stay safe, a lot of mornings, you know, there would be an incident, being honest with you".

(Katrina, Autism Carer)

Dementia carers also spoke of having to 'fight' and 'beg for help' in carrying out tasks like the changing of the PLWD's incontinence pads which was often a trigger for physical and psychological harm to family members. Mairead outlined her experience of trying to access rehabilitation for her father when he had a stroke a year after being diagnosed with dementia. Initially, he received rehabilitation and there were some improvements in his mobility however, the development of agitation resulted in his rehabilitation being terminated due to safety concerns. This resulted in him returning to live at home to be cared for by his 80-year-old wife with Mairead and his other adult children (not all living locally) helping out on a rota basis. Mairead spoke of their battle to access the necessary care and support.

"We basically begged and pleaded to get a third call during the day, when mam had her knee surgery, because she was the other person, if we needed to change him, she would have always been the one other person but then when she was laid up, we needed two of us there and it just, like I live an hour from where my parents live and I have my own kids and stuff, so it was, you know, this isn't possible for to come and change him at lunchtime, is there nothing you can do. So, we did get, they granted us a lunchtime call".

(Mairead, Dementia Carer)



Mairead went on to reflect that there appears to be no regard or duty of care to family carers by the State or the HSE. In contrast with the total lack of protection for Mairead and her 80-year-old mother undertaking a task known to put them at risk of harm, service providers walked away from providing care when staff were deemed to be at risk,

"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 Older, the Manager of Older Persons 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 commented on the lack of understanding and compassion by the HSE and the difficult knock-on impacts for the family including the criminalisation of her father's behaviour.

"I was so shocked. This was ten past four, the evening call was due at six o'clock and she was telling me that care had been withdrawn with immediate effect, all care. And I was like, you know, I was like, 'But, but, but, but, like this man had dementia' like I mean he wouldn't have known what he was doing, and she was like, one of, 'I have a duty of care to my staff and-' this, you know, all of this, so, yeah.....And she was suggesting that we put my father in an ambulance and put him into the General Hospital, you know...So, look, to cut a long, I know, a very long story short, we fought it and we got his care reinstated and it was outsourced then to an agency in the town that my dad lives in and they were absolutely spectacular. They, you know, they obviously trained their staff, they obviously, you know".

Yet, for Jennifer when it was suggested that the PLWD may pose a risk to grandchildren living with her, professionals acted immediately to report this concern, but offered no extra support to her mother.

"Everything obviously has changed, craziness with two children. So, she got very aggravated. She doesn't mean it but like sometimes she would push them out of the way or she'd scream at them. So, when she was going up for her reviews with these consultants she explained, she told them, she keeps saying my head, my head hurts from the noise and she would explain it to them, and it was getting on top of her. So they had to ring Tusla and get the guards involved, make sure the children were safe... It was awful like even right now it takes me back years because I'm trying to mind her, mind the kids, and I have all these people telling me, it's unsafe for her to be here but yet there's no services there".

(Jennifer, Dementia Carer)



Patrice who cares for her husband with dementia reported how when she explained to her GP that at times, she had to lock her husband in a room to protect herself from his physical violence towards her. This disclosure resulted in Patrice being referred to the local Safeguarding and Protection Team as it was deemed that Patrice was being abusive towards her husband.

Dementia carers reported that supports and services that could alleviate some of the responsive and harmful behaviours are often limited due to qualifying criteria such as age.

“ Because she was so young, she is not allowed. She has to go through the mental health clinic, because the services for someone with dementia they only come into effect when she is sixty-five, old age...She’s not allowed into a daycare centre because of her diabetes and her insulin injections, insurance-wise she’s not allowed into a daycare centre because they can’t- we need a full-time nurse in a daycare centre. And the daycare centres don’t operate that way, or they are not insured. ”

Jennifer, Dementia Carer

Family carers and professionals reflected that even when the PLWD qualifies for services, the limited time slots offered and lack of consistency in carers who are providing support, do not always fit with the needs of PLWD or the needs of adult children who are family carers, who are also in employment and caring for small children like Jennifer. She reflected that services are not a substitute for family care just an add-on, which in some instances can exacerbate not ameliorate the situation.

"The dementia girl she comes for two hours but like Mam doesn't know who she is. So, Mam is like up in a heap when she comes, 'Who is this person?' and then she's exhausted after it. As much as the services are great and because she only sees her once a week she doesn't retain it. So, it's like yesterday evening when I came home, and the carer was after leaving mam was in foul humour because she was so confused as to who the person was. So agitated and so exhausted then as well because she gets so tired so easily. I had a really bad night with her last night because of it you know what I mean trying to settle her".

((Jennifer, Dementia Carer)

In order to spend time with their children, continue working, and look after their wellbeing, family carers like Jennifer must find their own solutions, bearing the financial cost themselves,

“ I pay a lady that comes when I go to work, now she’s absolutely fantastic, she’s unreal. But like giving three half hours a week, like what services are there? They don’t allow you go off and work, you either have to be a fulltime home carer with her or you pay for it out of your own pocket. ”

Jennifer, Dementia Carer

When the family carer can no longer live with the aggression or have the energy to fight for every bit of support, often their only option is nursing home care for the PLWD and even that is not a simple process.

"The last thing they said in the dementia clinic was 'Look unfortunately this is it now you just have to try and eventually get her into a nursing home or something'. But there's too much of her mind. She falls short because physically, she is a capable woman you know she's able to move and walk around and stuff like that but that's why it's limited in what she gets".

(Jennifer, Dementia Carer)

Another significant challenge raised by several professionals was the issue of the nature of family relationships, situations of past abuse and a care recipient's insight into the level of care being provided by the family carer.

"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 recognise 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 Senior Manager)



Professional Helplessness and Inability to Respond

Autism and dementia professionals spoke at length about their difficulties as health and social care professionals when trying to provide the necessary help and support within the confines of how current systems are structured and function. Many reflected on their immense feelings of helplessness and frustration in relation to their inability to respond to the needs of family carers experiencing carer 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

Professionals highlighted the link between carer harm and the absence of appropriate condition-responsive services such as support workers for PLWD to continue with activities like walking to help reduce their feelings of agitation.

"It was just that old thing about what constitutes care, what people really need, and you know that focus on personal care. For a lot of our patients and families, it's just not relevant. They are not giving personal care, but I had a lovely couple the other day and all he really needs is someone to accompany him down to his farm, walk around, you know spend an hour and it reduces all his agitation, but his wife feels completely stuck and she's really distressed. He's shadowing her but you know if she could just get a package which would include just somebody coming in and being with him, like accompanying him".

(Dementia Focus Group Participant)

Despite a commitment by the HSE to make available home support hours for PLWD, other than personal care hours, in most areas these cannot be accessed as these participants noted:

"There are some dementia home support services available by the HSE you know, who in principle should be supplying that kind of social care hours for people, it's not- just if you get public health nurses who are saying 'We only do, only put in for practical care' that's absolutely nonsense. I mean I'm looking at a memo on my desktop at the moment from February 2021, from the HSE, the Assistant National Director of Operations for Services for Older People stating that home support service hours are available... We can't get answers on the ground though. I've sent loads of emails wondering where the dementia-specific hours have gone, no one is coming back...they have disappeared".

(Dementia Focus Group Participant)

In some areas, there are age restrictions on what supports can be provided to a PLWD or an autistic adult or service/organisational specific criteria that impacted on professionals' ability to respond.

"If you are under sixty-five and you don't have an intellectual disability you won't come to us, we don't take it. We might be more looking at the families' responses to the young person then because if they are assaulting sometimes families then are restraining physically, chemically, and it almost flips that we then are taking the case because the parent in attempts to defend and protect themselves ends up mistreating the person with autism".

(Autism Focus Group Participant)



Professionals reflected on the difficulties of balancing the needs and protection of all family members in situations of carer harm. They repeatedly expressed their feelings of frustration and helplessness about their inability to respond or to offer any kind of concrete support or help. Some reported that they had no ability to respond appropriately, even to crises referred to them.

"What happens is that, if it's an emergency, we will ask 'Are there other children in the house?' And the conversation will go along the lines of 'Can the child who is being aggressive be removed from the home? Have you somewhere else for them to go?' And they will say 'No'. And then we'll say 'Well, can you send the other children somewhere for the time being?' And that's normally what happens. Because we'll say 'Well we are not taking your children into care, we can't take your child into care because we have nowhere to put them'. And it seems very unfair to take the other children into care because we can't take the child in with the [additional] needs. It's going to be very upsetting for them, so can those children go to a family member and what you normally find is that family members are more than willing to take those children in".

(Autism Focus Group Participant)

"I suppose the harm that we would really see is this overwhelming feeling of helplessness...Now we get the crisis calls so it will be a Sunday at four o'clock in the afternoon, it will be the Guards calling saying 'We've been called to this house this person has moderate to severe autism they are assaulting their parents they have assaulted their sibling. What are you going to do for us, what can you do?' We will be on the other end of the phone saying nothing".

(Autism Focus Group Participant)

Professionals reported that they felt 'useless' working in a context where there was little acknowledgement that protecting carers from harm is extremely difficult in circumstances where the necessary legislation or appropriate services and supports cannot be accessed.



The significant negative impacts on families and family relationships were also highlighted.

"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 [Name] 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)

"I find at the moment even like you were saying there the people are calling us useless. Sometimes you do feel useless as well because you are like what can I do? Like it's banging your head constantly like trying to escalate this issue, this person needs a place of safety for themselves and for the people who look after them. We need to sort this situation. Like there's huge amount of collaborative work going on out there at the moment but there's no money, and there's no staff, there's no places for people to go, suitable places".

(Autism Focus Group Participant)

3. What Helps?

Family carers and professionals had many ideas in relation to what can help in situations of carer harm and also suggestions about what works from their own experiences. The key elements are outlined in the next section.

Advocacy

Advocacy was identified as critically important. However, it was acknowledged that family carers have different types of resources such as skills, time, education, and finances; this will influence the scope and effectiveness of their advocacy. Hence, family carers felt it would be very helpful if they had:

- Access to practical representation and professional advocacy support from organisations such as Family Carers Ireland when attending meetings with educators, the HSE, Disability Managers or other service providers.
- Assistance with identifying power holders, who can deliver on what the family carer/ autistic person/ PLWD needs e.g., name and contact details of the person they need to contact in relation to the specific issue such as the disability manager, manager of older persons services or the local politician.
- Help with writing letters/emails to key stakeholders.
- Support with social media and interviews when engaging with the media.

It was suggested by some that a collective advocacy approach should be taken in relation to getting the services and supports family carers, autistic people and PLWD need. The collective advocacy group should include all key stakeholders: family carers, FCI, educators, Gardaí, service providers and professionals working with autistic people and PLWD.



Assessment

It was acknowledged that there is a need for routine and proactive assessment of family carers' support needs, coping capacity, and the impact of caregiving on their physical and mental health. As part of this assessment, family carers should be asked whether they have experienced carer harm.

At a broader level, two solutions for meeting needs were proposed:

- Introduce legislation to ensure recommendations of assessments of need are resourced and implemented. Currently, children have a statutory right to an Assessment of Need if their parents/guardians believe them to have a disability under the Disability Act 2005. However, the State is not obliged to provide supports to meet any needs identified. PLWD have no legal right to an assessment of need or provision of home care/supports.
- Change the current funding model so it is linked to rights-based care provision.

Collaboration, Building Links at the Community Level and Signposting

Collaboration between organisations and service providers will enable resources to be pooled and avoid duplication. This can be achieved by joint working protocols and the setting up of referral pathways and services.

Family carers and professionals identified a number of examples of beneficial collaborations:

- Meitheal, a Tusla-led early intervention model brings together parents, schools, youth services, family resource centre staff, medical practitioners, Gardaí, and all other parties with an interest in the child's life. This was experienced as beneficial in terms of taking a holistic approach that supported not only the autistic child but also the whole family unit.
- Linking in with Community Gardaí, being able to call on them where support and help are needed. Involving the Gardaí routinely in local area planning forums and case conference/care planning meetings.

Signposting between organizations and service providers was also identified as important, particularly with the scarcity of formal care and support services. It can help family carers access some level of support where at their first point of contact e.g., Primary Care Centre they are directed to local peer support networks and resources like those produced by Family Carers Ireland, Middletown Autism Centre, and the Alzheimer Society of Ireland and for information on entitlements to local Citizen Information Services.

Finally, it was suggested that FCI could collaborate with the Alzheimer Society of Ireland and other organizations in the dementia field, and AslAm and other autism organisations and use their information and education resources to share/signpost to family carers. This would avoid the need for FCI to use their resources to set up separate education and information resources on specific disabilities.

Education and Training

For autistic children/adults, PLWD and family carers, information and knowledge on their disability are essential for understanding and supporting the person. Knowing their diagnosis and what it means gives the autistic person the tools to regulate their behaviour and provides PLWD with strategies for compensating for memory deficits.

Key areas to be addressed by autism education programmes for family carers of autistic children and adults were:

- Understanding autism and neurodiversity;
- Effective communication;
- Triggers and ways of identifying these in relation to each individual child;
- Understanding of 'meltdowns' and guidance on how best to respond;
- Impact on siblings and supports that may help them;
- Awareness of what is not acceptable behaviour;
- Self-care - understanding that what the autistic child/adult says is not personal;
- Strategies for staying safe and keeping other children in the household safe.

Key areas to be addressed by dementia education programmes for family carers of people living with dementia were:

- Understanding dementia, the different types of dementia and their symptoms;
- Arrange for professional experts to facilitate sessions for family members caring for a person with Frontal Temporal Dementia and Younger Onset Dementia;
- Effective communication;
- Understanding responsive behaviours, and what might trigger them;
- Guidance on managing responsive behaviours to ensure the family carer's reaction does not escalate the behaviours;
- What are the things in the environment that could perhaps be adapted to reduce instances of responsive behaviours?
- Self-care - understanding that what the PLWD says is not personal;
- Awareness of what is not acceptable behaviour within the context of dementia caregiving;
- Provide opportunities for role modelling for family carers. For example, witnessing what a carer may see as embarrassing behaviour by the PLWD being accepted/ normalised by others. This can help to lessen triggers for conflict and family carer isolation;
- Strategies for staying safe;
- Provide information on health and social care processes like multidisciplinary team (MDT) meetings or case conferences and the importance of attending.

Helpful suggestions for delivering education and training sessions:

- Facilitation by an expert in the field enables explanations to be provided, validation of the carers' feelings and acknowledgement of their needs;
- Provide practical information and advice;
- The format is important to make people feel safe and secure enough to share their experiences. Discussion groups work best where the group is split by relationship to the person with a disability (Autism carers – Group 1 parents, Group 2 siblings; Dementia carers- Group 1 spouses/partners, Group 2 adult children). Sessions should progress from the general to the individual: understanding autism/dementia, communication, self-care, stigma, what is responsive behaviour and how to manage it.
- Be aware that it takes time for participants to open up about their personal experiences.

At a wider societal level, increase awareness of autism and dementia and equip local communities and those engaging with autistic children/ adults and PLWD with the knowledge and skills to communicate and support them e.g., provide autism and dementia-specific training to the Gardaí. Be aware however that education is not the answer to all situations where family carers are experiencing harm.

Peer Support

The setting up of peer-support groups in every community was seen as hugely beneficial to family carers of autistic children/adults and family carers of PLWD. Peer support groups can:

- Create spaces for carers to share their experiences of carer harm and understand they are not alone in managing responsive behaviours. These sessions could be complemented with professional expert input and support.

Set up specific peer support groups for siblings of autistic children, giving them an opportunity to voice their worries/concerns.

Services

For the autistic child/adult and their family carer

- Early intervention is critical for autistic children. Assessment to identify triggers for emotional overload resulting in 'meltdowns' can inform strategies for responses. Input from professionals who have observed the child at home would be beneficial and necessary in many cases.
- Organise for a behavioural therapist to engage with the family in order to develop a behaviour management strategy beginning when the child is very young and reviewing it annually. The plan developed can be implemented at home and in school.
- Where waiting lists are in place, use the National Treatment Purchase Fund for the purchase of community services or essential therapies such as speech and language or occupational therapy.
- Ensure autistic adults can access their service five days a week.

For the person living with dementia and their family carer

- Early intervention to support the PLWD was seen by participants as crucial to preventing carer harm as it can bring PLWD and carers into the support system.
- Where there are ongoing issues around responsive behaviours, linking the PLWD to HSE Mental Health for Older Persons Services in a timely manner can help resolve some of the behaviour.
- Providing in-home respite provision rather than providing respite in an environment unfamiliar to the PLWD, which can be very upsetting for them and their family carer.
- Providing social care support workers for PLWD to enable them to continue engaging with interests and activities in the community, while providing respite for the family carer.
- Provide opportunities for one-to-one meetings with a professional knowledgeable about dementia to make it easier to talk through family carer concerns/worries for the PLWD.

Therapy

- Provide family therapy which focuses on the needs and impact of carer harm on the whole family unit. Give opportunities for each member of the family to voice their worries/concerns and wishes.
- Make available counselling – help family carers work on boundaries, in terms of carer well-being, and what they can reasonably expect of themselves; and how to hold boundaries in terms of others' expectations; help manage their feelings of stigma, shame guilt, stress, and burnout.

World Café Findings

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. World Café co-design sessions centred around three core questions:

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

Participants in the autism and dementia World Café spoke about the power of language, how it is value-laden and evokes different responses. Participants reflected that the term 'Carer Harm' is not clear, and it could be interpreted as the carer causing harm. 'Carer Harm' used in relation to autistic people could stigmatise them further.

Alternative terminology suggested included 'carers experiencing harm' which would keep the focus on the carer and not the person causing harm; 'harm that has been done' might lessen the blame when the behaviour did not involve intent; 'carer hurt' but does this capture the physical and emotional/psychological experiences of being hit or verbally abused by the person being cared for?

It was felt that the outcome of behaviour, whether intentional or unintentional, that caused harm to family carers had to be 'named' if family carers experiencing harm were to identify themselves, disclose the harm and get support. It was agreed that the information leaflets being developed should include a definition of 'carer harm'.

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

In response to this question, participants suggested:

- Include carer harm as a topic in education and training courses for family carers of autistic children/adults and PLWD; raising awareness that carers can experience carer harm.
- Include the topic as part of standardised assessment forms/processes.
- Provide information on carer harm to family carers as part of the information on symptoms at diagnosis.
- Raise awareness of carer harm among health and social care professionals including GPs, hospital doctors, Public Health Nurses, occupational therapists, physiotherapists, speech and language therapists, social workers, home care workers, the Gardaí and wider community.
- Professionals engaging with family carers should ask about 'carer harm', making it part of 'normal' conversation. Use an approach similar to that used in relation to domestic violence, where pregnant women are asked about their experiences.
- Important to let carers know they are not alone, nor are they 'bad' parents. To encourage disclosure, remove the blame to reduce the shame.
- Acknowledge some family carers may not understand/perceive the behaviours they are experiencing to be harmful or may define their experiences differently.
- Highlight the need to avoid stigma but also acknowledge this is not a normal aspect of caregiving.
- Raise awareness of carer harm, using a similar process to that used for domestic violence, e.g., poster advertisements.
- Raise awareness of their human rights among family carers.
- Share information leaflets with peer support groups.
- Where family carers share an experience of being physically or emotionally harmed, professionals should name the experience as harmful. They should not minimize the experience due to having no formal supports to offer. They should not shy away from pointing carers towards peer supports e.g., face-to-face and online.
- Information on services including advocacy services is important to include.
- Information that will let carers know what to do, help them talk about 'carer harm' if they are experiencing it and reach out for support is also important.
- There also needs to be information aimed specifically at men who may be experiencing carer harm to encourage disclosure and to combat the idea that it's their job to keep the family safe.
- Develop a Directory of Support Services.



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

Social Workers and advocacy organization participants acknowledged that the scarcity of services and supports they have to offer to family carers, their autistic children/adults and PLWD made it difficult to support family carers. However, they did identify services and supports that could support family carers and help prevent carer harm. These included:

- Respite services, after-school clubs, and youth clubs for autistic children/adults; put in place behavioural therapist support; being able to access funding for individualised services.
- Have care plans drawn up by practitioner's expert in the field of autism/dementia in partnership with families.
- Facilitate carer peer support groups in parallel with day centre/school attendance.
- Appoint a named person/body responsible for autism and dementia services and support to prevent service users and family carers from being passed to different services without success.
- Recognise and acknowledge how serious and dangerous carer harm is including sibling-to-sibling violence/harm and psychological harm.
- Make carers feel listened to with actions as an outcome of what they have said. Professionals should ensure they do not come across as being patronising.
- Consider and assess family carers' needs through a human rights lens. Take the lead from the carer.
- Responsibility on professionals to educate themselves on 'carer harm.'
- Provide training to professionals on how to engage with autistic people and PLWD.
- Develop and support family carer-led, peer support-driven education and support initiatives.
- Strive to remove the 'hero' narrative around family caregiving. Acknowledge the multidimensional and complex nature of carer harm.
- Look at building partnerships between organisations to create a knowledge pool on 'carer harm'. From this knowledge build evidence of the scope of 'carer harm' to get buy-in from funders and justify funding of supports for family carers.
- Advocacy is very important as a form of support, as are early intervention and counselling.

Findings from the focus groups, narrative interviews and World Café sessions were used to inform the focus and content of the following information and awareness-raising booklets and best practice considerations:

- [FCI Carer Harm Information Booklet](#)
- [FCI Carer Harm and Autism Information Booklet](#)
- [FCI Carer Harm and Dementia Information Booklet](#)
- [FCI Supporting Family Carers Experiencing Carer Harm: Best Practice Considerations for Professionals and Service Providers](#)

Discussion

This study set out to explore the perceptions and experiences of family carers of autistic children/adults and family carers of people living with dementia who have experienced carer harm by the person they are caring for. It also examined how professionals and service providers can better support family carers who are experiencing carer harm. There is little in the existing literature which focuses on this important emerging area of practice and only a handful of studies exist that focus specifically on the topic of carer harm. The issue of family carers who have experienced domestic harm has largely been overlooked by statutory organisations, perhaps because they often do not fit the traditional patterns of abusive relationships, and the complexities of the caring role can make standard safety interventions unsuitable (Warburton Wynn 2023).

The starting point for this study was not to uncover whether harm experienced by family carers is a 'type' of abuse. Rather, we considered it important to explore family carers' experiences and ways of understanding harm, current responses from service providers and professionals, and to begin to identify what helped family carers to cope. We also considered it important to explore the experiences of how those who are in a position to identify, support and work alongside family carers experiencing carer harm, in terms of what helps and what are some of the current challenges.

While in no way definitive, this study drawn from a small sample is helpful and instructive in terms of shedding light on current experiences that family carers who have experienced carer harm have had when engaging with service providers and professionals here in Ireland. The findings indicate that we may still have some way to go toward understanding the dynamics and experiences of carer harm and incorporating such an understanding into our systems, services, and responses. The following discussion will point towards future research and practice directions and, where applicable, point to what we are doing right and what helps.

Defining and Understanding Carer Harm

Family carers and professionals who participated in this study shared their discomfort with the terminology of 'carer harm.' For many, the language was problematic as participants did not feel it adequately reflected that the harm experienced by family carers was often neither wilful nor intentional. The professionals who participated in this study identified the significant challenges and barriers to working with affected families. Studies which have examined the related and overlapping concept of Child - Parent Violence and Aggression (CPVA) also found there was a lack of awareness among parents, carers, young people and even professionals about the issue (Holt and Brennan, 2022). Our study suggests the need to revisit the working terminology of 'carer harm' as defined by Isham et al. (2020) and raises the question of considering alternative terminology, for example, 'carers who have experienced harm' or 'carers who have experienced harmful behaviours.'

Findings suggest the sensitive and sometimes taboo nature of this type of harm with disclosure frequently being accompanied by feelings of stigma, shame, and guilt. There was a general lack of awareness from family carers as to what is and is not acceptable behaviour. Whether due to a lack of awareness or due to stigma, family carers do not report or speak easily about the harm they experience

in undertaking their caring role. Professionals indicated that often a crisis situation or event led to disclosure however for some family carers, feelings of guilt were further compounded by the attitudes and lack of response by professionals and service providers.

Many of these feelings were attributed to family carers' perceived reluctance to disclose sensitive information that could be interpreted as shameful or embarrassing, or as contravening norms about family life and domestic space (Isham et al.2020; Crockett et al., 2018). Previous research into CPVA indicated that 40% of parents or carers who experienced violence by their children refused to report it. This can lead to an inconsistent and patchwork provision of support for families and a lack of understanding about how to access it (Holt and Brennan, 2022).

Family carers in this study expressed fear and anxiety in relation to the perceived safety of other family members such as children and that disclosure might lead to unwanted interventions such as residential care in order to keep family members safe from harm. There continues to be a misconception across society that child-to-parent violence is a symptom of parental failure, and the harmful behaviours are highly stigmatised. Parents/carers can feel immense shame and isolation, which prevents them from seeking support (Holt and Brennan, 2022). There is a point, however, where the behaviour of the person being cared for, whether intentional or not, can fall into the category of being harmful. Recognising, reporting, and responding to carers at risk of harm will not always be easy as the situation may be complicated by carer denial, guilt, or a sense of loyalty to their loved one—but it is critical (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019).

The study identified a wide range of types of harm experienced by family carers including shouting, screaming, damage and destruction of personal possessions or the family home, a constant sense of threat and significant levels of physical violence as well as the knock-on emotional and psychological distress. Findings suggest that many family carers had to put in place safety plans and safeguards in order to protect themselves and other family members such as other children or extended family members from serious physical or life-threatening harm.

Family carers and professionals reported that family carers and the person they are caring for can also experience harm as a result of unrealistic expectations and pressure and in how the education and the broader health and social care system treated them. There was frequently an expectation that family carers would cope with huge amounts of care alone in situations where professional carers would not be required to with significant amounts of unmet need highlighted as a result of inadequate provision of intervention and support services. In some instances, family carers were forced to abandon the person they were caring for in order to access the necessary support, but also to keep themselves and other family members safe.



Empowerment Through Diagnosis and Disclosure

Diagnosis and early intervention were identified as an important first step by family carers and professionals in helping family carers to understand the changes in presenting behaviours by the child/adult they were caring for and to empower them to better cope. Often there was a protracted journey to receiving a diagnosis which then impacted on access to early intervention and support. Findings suggest that family carers who have accumulated the most social capital in terms of levels of educational attainment and access to financial resources were better able to self-advocate and bypass the public system to gain a diagnosis and put in place supports or access help such as behavioural training.

The importance of professionals engaging with both the child or adult receiving the diagnosis and their family carer openly and communicating the diagnosis in a way that is appropriate and understandable to both, is central in building relationships of trust between the child/adult, their parent/family carer, and professionals. Communicating disclosure in an individualised way, appropriate to the individual's insight and understanding, empowers them to engage with professionals and services, enabling their family carer to continue in their caring role for longer. Where this does not happen, it can have negative impacts on the caregiving relationship and dynamic. Professionals leaving it to the family carer to relay diagnosis and implement decisions, for example, cessation of driving for PLWD, creates situations where the family carer is more likely to be exposed to harm. This study also highlights the need for awareness and increased, targeted and preventative supports at key transitional stages such as puberty (autism) and increasing or changing care needs (dementia) as the intensity of responsive or harmful behaviours can increase at these times.

A Fragmented Health and Social Care System Unable to Respond and Protect

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. Findings indicate the significant challenges for family carers in navigating a fragmented and complicated health and social care system. Family carers spoke of the battle of having to beg and fight for help and support. The negative impacts on family carers and the person they were caring for when unable to access the appropriate, condition-specific services were repeatedly highlighted.

This study suggests that pressures such as staffing and resourcing within organisational systems and structures result in services taking a 'silo' mentality, imposing strict diagnostic categories for access, resulting in families living with the risk of harm as the child/adult exhibiting the harmful behaviour is not getting any professional input. There was also a failure in many instances to acknowledge and address the family carers, siblings, or other family members' right to live in a safe environment indicating that this is an emerging problem for families and practitioners. 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). The complex multi-faceted nature of harmful behaviours and the real risk this poses to not only the parent/carer but also to siblings must be recognised (Thorley and Coates, 2018).

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.

There is confusion and ambiguity for family carers and professionals as to the remit of different organisations such as the HSE and service providers in relation to autism and there appears to be a lack of clarity as to who is responsible for providing supports and services to autistic children and adults leading to many falling between the cracks. A vacuum exists as to where children/adults with 'just' autism fit and what to do when children are a danger to themselves and/or their family/professional carers – who takes charge? The significant issues of waiting lists, staffing, and resourcing of HSE Disability Teams and service providers were identified as contributory issues. For people living with dementia, a predominantly bio-medical approach was evident whereby the solution to responsive behaviours was a referral to HSE Mental Health Services for Older Persons for assessment for medication. The provision of individualised, dementia-specific, psycho-social support was extremely difficult or impossible to access.

Even when vital supports such as respite were offered, the child/adult's lack of understanding or insight into the need for services to give their parent or family carer a badly needed rest often resulted in the offer of respite not being taken up. The difficulties with accessing appropriate services and supports also had an impact on the career/work opportunities of family carers.

Limited time slots available for home support do not always fit with the needs of family carers or a PLWD where regular and consistent input into building relationships with professional carers is key. In order to spend time with their children, continue working, and look after their wellbeing, family carers must find their own solutions, paying for private carers to cover while the family carer works. The increased and unsustainable demands placed on family carers lead to a crisis and they come to a point where they can no longer ensure their own safety and protection or that of other family members. The findings of this study suggest that support offered to PLWD and their family carers should have a person-centred approach to meeting individual needs. The safety and welfare of persons with dementia and their family members residing in their own homes may be jeopardised in the presence of carer harm. Greater awareness is required in the community regarding the well-being of these persons (Tyrell et al.2016).

Supportive Interventions

One of the main responses evident in the findings was for professionals and services to train the parents/family carers. Training such as generic parenting courses are offered or suggested as a solution when there is nothing else available, even where parents/carers have already done various, more specific courses, including sensory processing, behavioural training and non-violence resistance training.

This shifts the burden of responsibility back to the family carer as service providers and professionals can take the position that the family carer has received training and therefore should be able to now deal with harmful behaviours. The focus on education and training of family carers as the main response to prevent carer harm points to an acceptance, normalisation almost, that harm is part and parcel of providing care to a person exhibiting harmful behaviour. Hence, family carers endure this harm and do not raise the issue. In the UK context, the introduction of multi-agency supportive interventions, as a proactive approach to reducing the risk of harmful behaviours, has been identified as important as well as a non-criminalising route to support families of children or adults who display challenging, aggressive, and violent behaviour (Thorley and Coates, 2018).

Participants identified a range of supports and interventions which they deemed would be helpful when preventing and responding to carer harm ranging from advocacy, assessment, collaboration, tailored and individualised service provision, peer support, signposting to services and taking a 'whole family' approach. However, professionals and service providers had to operate in a context where there was little acknowledgement that protecting carers from harm is extremely difficult in circumstances where the necessary legislation or appropriate services and supports cannot be accessed.

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. Professionals felt frustrated, useless, and helpless as even in crisis situations, they had nothing to offer. Effective protection and safeguarding needs to do more than simply wait for a situation to reach a crisis point (Keeling, 2017) and legislation has the potential to empower the agency of professionals and service providers to take decisive action in a timely manner. 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).



When working on behalf of the state or welfare bodies, professionals are directly and indirectly invested with power and responsibility to interpret the law, policy and organisational guidance about how families are (or are not) engaged with and supported (Johnson, 2012). This underlines the importance of examining the social and cultural factors that shape the way professionals understand, think about, and communicate ideas relating to risk and vulnerability, particularly when there is limited formal guidance available to orientate their practice (Johnson, 2012), as is the case with carer harm. 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.

We echo previous calls that if Government truly values family carers and respects them as the bedrock of the health and social care system, then they must develop and commit to policies to better support carers including enforceable rights, accessible and dependable services and a comprehensive framework to prevent and protect family carers experiencing carer harm (Family Carers Ireland, College of Psychiatrists of Ireland & UCD, 2019). Finally, findings add weight to previous calls for family carer assessments to cover issues of harm and protection in relation to the individual's caring role, as well as mandatory training for professionals in how to ask these questions (Warburton Wynn, 2023).

Study Limitations

This study is a small-scale exploratory study that used a purposeful sampling approach and is, therefore, 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. Similarly, 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.

Given some of the ethical and practical challenges inherent in working with family carers and professionals in relation to such a 'hidden' issue, this study provides some important empirical insights about carer harm. There is nevertheless ample scope to build on its initial findings. As with all qualitative research, the insights it generates are sensitive to and grounded in their social, cultural and organisational contexts. 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. The use of alternative and additional research methods could also provide critical and different knowledge about how family carers experience care harm and how health and social care professionals identify and respond to carer harm.



Conclusion

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. This study has begun to shed light on the topic of carer harm however further research is required in order to gain a more in-depth, nuanced understanding of family carers' experiences of carer harm in relation to a range of disabilities and conditions as well as exploring further the impact on the child/adult causing harm as well as other family members such as siblings.

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 however 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.

Through the development of information booklets for family carers and best practice considerations for professionals, we hope to have taken some small but important steps towards raising awareness of the issue of carer harm for family carers and professionals but also for wider society.



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