

Research Conference 2025

Partnership from Research to Practice

Hosted By



Family
Carers
Ireland

No one should have to care alone



3rd December 2025: Ashling Hotel, Dublin

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Acknowledgements

The conference was made possible by the enthusiastic involvement and contributions of a range of people. These include members of the conference Steering Committee, including Johanne Powell, who also skillfully chaired the conference. Family Carers Ireland (FCI) is grateful to the conference speakers for sharing their knowledge and research findings as well as for highlighting potential paths forward in research and policymaking. We appreciate the guidance of Dr Emma Dorris, Engaged Research Manager at UCD Research and Programme Manager for the PPI Ignite Network at UCD, for her input into the conference planning and for her facilitation of the roundtable discussions. We also wish to express our gratitude to those who facilitated discussions at individual tables and the volunteers from UCD who helped the day run so smoothly.

We appreciate the invaluable inputs of attendees, which included people with a range of experiences of caring as well as people who came from different sectors including academia, civil society, health and social care, Government departments and statutory bodies. As ever, we are especially grateful to the family carers and members of the Public and Patient Involvement Panel (PPI) at FCI who shared their experiences of caring and the challenges and benefits of being involved in research.

Introduction

Now in its fifth year (2025), the Family Carers Ireland Research Conference is an annual event hosted by FCI that brings together stakeholders to engage with research on family caring.

It brings together family carers, researchers, health and social care practitioners, and representatives from government departments, statutory bodies and NGOs. The conference provides a forum for presenting recent carer research, examining key challenges in family caring, and considering implications for policy and practice.

Family Carers Ireland convened an advisory panel of family carers and academic and civil society representatives to co-develop the agenda and discussion topics, with the aim of ensuring an inclusive and accessible event relevant to the full range of stakeholders.

The conference took place on Wednesday 3rd December 2025 at the Ashling Hotel, Dublin, and was attended by over 60 participants. Proceedings were opened by Johanne Powell, former carer and President of the National Carer Council. This was followed by a series of research presentations, each accompanied by contributions from individuals with lived experience of caring and involvement in Public and Patient Involvement (PPI) processes, reinforcing the central role of lived experience throughout the programme.



The conference agenda included:

- Guest speakers with direct experience of translating research into practice, highlighting tangible outputs and real-world impact;
- Contributions from carers involved in PPI activities, offering lived experience perspectives alongside research findings;
- Small, mixed roundtable discussion groups exploring barriers to, and solutions for, translating research into practice;
- Informal networking opportunities over refreshments and lunch.

Setting the Scene: Sharon Foley, CEO, Family Carers Ireland

Family Carers Ireland's new CEO, Sharon Foley, opened the conference by welcoming attendees and reflecting on the importance of research in driving meaningful change for family carers.

In her remarks, Sharon emphasised that research is most effective when it informs practice and policy. She noted that the conference provided an opportunity not only to reflect on existing knowledge, but also to identify persistent gaps and strengthen collective commitment to action in support of carers across Ireland.

Drawing on her experience of working in research, she highlighted the role of robust evidence in shaping policymaker thinking, the value of lived experience in challenging assumptions, and the contribution of research to strengthening organisations and influencing systems such as the HSE.

Reflecting the conference theme, Sharon underlined the importance of collaboration across academic, policy and lived-experience perspectives. She pointed to the diversity of the programme, which brought together academic insights, carers' voices, policy analysis and discussion on research communication, as evidence of a shared commitment to translating research into tangible improvements in carers' lives.

She highlighted the opening session on integrated care as a reminder that family carers must be recognised as key partners within collaborative care teams if community-based systems are to function effectively. She also welcomed the strong representation of carers across presentations and discussions, reinforcing the organisation's commitment to centring carer experience in research and policy dialogue.

Looking ahead to the later sessions, Sharon emphasised the importance of communicating research for impact and encouraged participants to actively engage in the roundtable discussions. She noted that translating evidence into action is critical to strengthening advocacy and ensuring that the needs of family carers remain at the heart of health and social care reform.





Section 1: Partnership from Research to Practice- Presentations

What Does 'Integrated' Mean for Us? Family Carer Inclusion in Interprofessional Collaborative Care Teams Integrating Community-based Care for Older People.

Dr Deirdre O'Donnell, UCD IRIS Centre &

Saoirse O'Mahony, Member of the ECLECTIC project Public and Patient Advisory Group

Dr Deirdre O'Donnell

Dr Deirdre O'Donnell presented research from the ECLECTIC project which examines how community specialist teams for older people develop the knowledge and skills required for effective interprofessional collaboration. The study is situated within Ireland's Enhanced Community Care (ECC) policy framework and the Integrated Care Programme for Older People (ICPOP), both of which aim to shift care from hospital settings to the community and to support older people with complex needs to live well at home.

The research responds to a significant policy shift towards team-based models of care. While multidisciplinary team (MDT) working is well established in acute settings, the development of integrated, community-based specialist teams raises important questions about how collaboration works in practice. The project explores what supports effective teamworking, what barriers exist, and critically, how family carers are included (or excluded) within these care teams.

Community Specialist Teams for Older People bring together nurses, physiotherapists, occupational therapists, speech and language therapists, social workers and dietitians under the governance of a consultant geriatrician. These teams undertake Comprehensive Geriatric Assessments (CGA) and provide short-term, community-based intervention for older people with complex needs. As Deirdre noted, however, assembling professionals “around the table” does not automatically result in effective collaboration; developing the skills, structures and shared understandings required for meaningful interprofessional working is an ongoing process.

The ECLECTIC study comprises three work packages: a realist review and synthesis of the evidence; in-depth case studies of four community specialist teams, including observations, interviews and surveys; and a synthesis phase focused on curriculum development. The presentation focused particularly on qualitative interviews with older people and family carers conducted as part of the case study work.

Public and Patient Involvement (PPI) has been central to the project from its inception. Public and Patient Advisors contributed to shaping the research questions, advising on study design, co-developing interview materials, and supporting interpretation of findings. Advisors also co-created narrative accounts based on anonymised interview transcripts, identifying key themes and critical incidents that illustrated carers’ lived experience of navigating integrated care systems.



Saoirse O'Mahony, PPI representative with the project

Saoirse O'Mahony, a member of the ECLECTIC Public and Patient Advisory Group, presented examples of these co-created narratives which highlighted both the potential and the limitations of integrated care in practice.

Carers described challenges including fragmented communication between services, unclear lines of responsibility, lack of a consistent point of contact and gaps between service allocation and delivery. Some experienced confusion about referral pathways and reported repeatedly contacting different professionals to progress basic elements of care. Others described emotional strain, isolation and exhaustion, particularly where short-term interventions did not translate into sustained support.

At the same time, carers also described positive experiences where they felt listened to and supported, particularly where a member of the team acted as an advocate or coordinator. Across the narratives, the importance of clear communication, recognition of the carer's role, and practical support with system navigation emerged strongly.

Drawing on both the qualitative findings and advisory group reflections, the presentation identified key mechanisms required for the meaningful inclusion of family carers within integrated care models including:

- Accessible and two-way communication;
- Transparency around care plans and entitlements;
- The appointment of a key worker or case coordinator;
- Practical navigation supports; and
- Policy commitment to adequately resourcing home support.

Overall, the research underscores that integrated care must extend beyond professional collaboration to actively recognise family carers as essential partners within the care team. Without clear coordination, adequate resourcing and effective communication, carers risk being left to fill systemic gaps, undermining the intended goals of community-based, person-centred care.





Family Caring in Later Life: prevalence, impact, and the need for policy support

Dr Christine McGarrigle, TCD

Ray Lucey, Member of Family Carers Ireland's Public and Patient Involvement Panel

Ray Lucey, PPI representative with the project

Ray Lucey, a member of Family Carers Ireland's PPI panel, opened the presentation by reflecting on his experience as a former carer and the importance of ensuring that research findings translate into practical and meaningful supports. He emphasised that while policy commitments are essential, they must be realistic, adequately resourced and implemented without delay. Too often, he noted, carers feel isolated and unsupported, navigating complex systems with limited coordination between departments and services.

Ray highlighted the importance of maintaining momentum in advocacy efforts, particularly in light of recent increases in supports for carers in national budgets. He stressed that continued engagement with policymakers, including the Department of Health, is critical to ensuring that research findings are acted upon rather than remaining aspirational.

He also underlined the vital role of PPI in strengthening research impact. PPI contributors help ensure that findings are communicated in accessible jargon-free language and grounded in lived experience. For Ray, the ultimate aim of research is tangible improvement in supports for carers and those they care for.

Dr Christine McGarrigle

Dr Christine McGarrigle then presented findings from The Irish Longitudinal Study on Ageing (TILDA), a nationally representative study of adults aged 50 and over in Ireland that has followed participants since 2009. The longitudinal design enables analysis of changes over time, including transitions in and out of caring roles and shifts in patterns of support.

The research examined both receipt of care and provision of care among older adults. Findings indicate that family care represents the largest and growing proportion of support provided to older adults. Between 2018 and 2021, the proportion of assistance provided by family members increased substantially, while privately sourced care declined and state-provided care remained relatively stable. This suggests that where formal supports are insufficient or unavailable, family carers are increasingly compensating for unmet need.

The study also examined the intensity of caring, measured through hours of care. Although overall caring levels rose during the COVID-19 pandemic before returning to pre-pandemic levels, the proportion of carers providing high-intensity care (defined as 50 hours or more per week) has remained consistently high, at approximately one-third of carers. Women were more likely to report caring across a range of relationships, while men were more likely to report caring for a spouse. A notable proportion of older adults also reported caring for friends or neighbours, highlighting the breadth of informal care networks.

Importantly, the findings demonstrated the impact of high-intensity caring on mental health and wellbeing. Carers providing 50 or more hours of care per week reported lower quality of life, higher levels of depressive symptoms, and increased stress over time compared with lower-intensity carers and non-carers.

The research also highlighted the economic value of informal care. Analysis of end-of-life care showed that a substantial proportion of care hours are provided unpaid by family and friends, representing a significant contribution to the health and social care system. This has important implications for policy and sustainability, particularly in the context of Ireland's ageing population.

Christine concluded that supporting family carers is essential not only for individual wellbeing but also for the functioning of the wider health system. As demand for care increases, insufficient formal service provision risks placing greater strain on family carers, with potential negative consequences for both carers and care recipients. Ensuring access to adequate home support, enabling carers to balance employment and caring responsibilities and maintaining ongoing engagement with policymakers are central to sustaining care in the community.



Two years on: Reflecting on the Impact of the Understanding Carer Harm Project on Policy, Practice and the Lived Experience.

Dr Sarah Donnelly, UCD

Sinead Tighe, Family Carer and Member of Family Carers Ireland

Dr Sarah Donnelly

Dr Sarah Donnelly began by acknowledging FCI for its partnership and support of this research, noting that the topic of “carer harm” remains sensitive and frequently taboo. The research project, conducted between 2022 and 2023, sought to better understand the experiences of family carers who experience harm from the person they are caring for – an issue that has historically received limited research and policy attention.

The study built on earlier research conducted in 2019 by FCI and the Royal College of Psychiatrists in Ireland, which found that 44% of surveyed carers reported regularly experiencing physical and/or psychological harm. While this survey highlighted the scale of the issue, little was known about the lived experience of those affected.

With funding from the Irish Research Council, the research team conducted secondary analysis of the 2019 dataset and identified two cohorts reporting high levels of harm: carers of children with autism and complex health and social care needs, and carers of people living with dementia. Narrative interviews were conducted with carers from both groups.

Participants described experiencing a spectrum of harm, ranging from shouting and property damage to significant physical violence and psychological distress. For some, transitional life stages such as puberty or cognitive decline associated with dementia were identified as triggers for escalating behaviours.

A key finding related to the role of systems and services. Many carers reported a lack of accessible crisis supports, alongside dismissive or negative responses from professionals. Some felt they were expected to manage levels of risk that would be considered unacceptable in formal care settings. In certain cases, when paid carers withdrew services following incidents, family members were left to continue caring in highly challenging circumstances without adequate support.

This led the researchers to reflect on the concept of “system harm”, where welfare policies, service gaps or professional responses compound stress and isolation. Carers described having to “fight” for assistance, often at moments of acute crisis. From the outset, the project aimed not only to document experiences but also to develop practical resources.

Outputs included:

- [A general information leaflet on carer harm](#)
- [A dementia-specific resource](#)
- [An autism-specific resource](#)
- [Best practice guidance for health and social care professionals](#)



These materials have been disseminated nationally and internationally through webinars, academic publications, conferences and policy engagement, including presentations to the Commission on Care for Older People, Social Justice Ireland, and policy working groups in Wales addressing violence and safeguarding.

Sarah also outlined the establishment of a Five Nations Working Group, bringing together academics across Britain and Ireland to examine how caregiving, safeguarding and domestic violence policies intersect. The group is analysing legislative and policy gaps and advocating for stronger statutory recognition of carers' assessment and support needs.

She concluded by emphasising societal interdependence: at different points in life, everyone will either give or receive care. Policy frameworks must reflect this reality and ensure that carers' safety and wellbeing are protected.





Sinead Tighe, Providing a carer perspective

Sinead Tighe reflected on her lived experience as a family carer for her young adult son Daniel, with significant support needs. She described the stigma and shame often associated with speaking about harm, noting that prior to engaging with the research she would not have felt able to publicly discuss these experiences.

Sinead described periods where behaviours became particularly challenging, particularly in public settings and the emotional and practical toll this placed on her and her family. Initially, when she sought support, she encountered barriers and was told that no appropriate therapeutic interventions were available. With support from FCI, she accessed behavioural therapy.

Through engagement with structured behavioural supports, Sinead described a shift in how she understood these behaviours. She moved from viewing them solely as problems to be managed, to recognising them as forms of communication. With guidance from behavioural therapy, she developed strategies to identify triggers, adapt routines and better interpret communication cues.

These strategies became particularly important as formal supports were withdrawn. Over time, Sinead reported greater understanding of her child's needs and increased confidence in advocating for appropriate interventions. She also emphasised the importance of behavioural therapy being available early in a child's development, rather than only after crises emerge.

As services transitioned from children to adult services, the existence of a structured behavioural support plan ensured continuity across professionals, including GPs, respite providers and disability services. Sinead stressed that carers are allies to health and social care professionals and policymakers. With appropriate respect, early intervention and collaboration, many challenging situations can be better understood and managed.

She concluded by highlighting the importance of listening to carers, recognising their expertise, and embedding behavioural supports and training into early intervention systems. She noted speaking openly about carer harm reduces stigma and improves outcomes for both carers and those they support.

Section 2: Using Research to Advocate for Change

Clare Duffy, Policy and Public Affairs Manager, Family Carers Ireland

Clare Duffy opened her presentation by acknowledging that, within FCI, the use of research to advocate for change often feels instinctive. However, she noted that articulating this instinct in a structured way reveals the complexity of the journey from research to policy.

She challenged the assumption that research influences policy in a linear or predictable manner. In practice, she argued, the relationship is complex, iterative and often messy. Research may directly inform policy decisions, but equally policy priorities can also shape the research agenda. In some cases, research and policy are co-designed, while in others they operate in parallel, intersecting only occasionally. Most often, she suggested, policy change emerges through a combination of these dynamics.

Clare emphasised that effective advocacy at FCI depends on robust, credible evidence to support engagement with government departments, elected representatives and public bodies. She also noted that research does not always need to have immediate policy change as its primary objective. Incremental contributions to knowledge, shifts in understanding and strengthening the wider evidence base are equally valuable and should be recognised within research impact frameworks.

She then outlined the “players” involved in moving from research to policy change including researchers across universities, NGOs and agencies; carers and those receiving care through PPI; funders; practitioners and healthcare professionals; policy intermediaries and advocates; policymakers; and the media.

Clare cautioned against using “policymakers” as a single audience. Effective advocacy requires identifying the specific audience being targeted; civil servants, Ministers, special advisers or parliamentary offices. She highlighted the role of policy intermediaries, including advocacy organisations, in translating research findings into accessible messages and targeted policy proposals.

The media, she noted, plays a particularly influential role. A concise statistic or compelling finding communicated effectively through broadcast or print media can open doors to policy engagement and accelerate change.

Clare then reflected on characteristics of research that have proven especially impactful for FCI. Research with clear purpose and real-world relevance is particularly influential. She highlighted the importance of identifying the intended audience, embedding strong PPI and producing clear, concise and communicable messages. Findings that can be articulated succinctly are especially valuable in political and media contexts.



She illustrated these points through three examples:

1. Carer's Allowance Reform

Research conducted in partnership with academic collaborators explored alternative models of Carer's Allowance, including a proposed Participation Income model. Detailed costings were undertaken by FCI and independently assessed by the Parliamentary Budget Office. This combination of robust modelling and credible financial analysis helped shift perceptions around the feasibility of reform, contributing to significant expansion of eligibility for Carer's Allowance. Clare noted that this progress would not have occurred without sustained evidence-based advocacy.

2. Young Carers

For many years, Census data significantly underestimated the number of young carers in Ireland. However, findings from the Health Behaviour in School-aged Children (HBSC) study indicated that 13.3% of young people aged 10–17 were providing care, equating to approximately 67,000 young carers nationally in that age group alone. This evidence provided a strong mandate for policy engagement contributing to formal recognition of young carers within government structures, references in national youth policy, targeted access routes in higher education, bursaries and dedicated funding streams.

3. Understanding Carer Harm

Clare described the Understanding Carer Harm research as particularly impactful in shifting policy discourse. While it did not immediately produce legislative reform, it brought a previously hidden and stigmatised issue into public and policy awareness. Drawing on the concept of the “Overton window” (the range of ideas considered socially and politically acceptable) she suggested that the research is helping move carer harm into more mainstream discourse, enabling acknowledgement, discussion and the conditions for future policy development.

In conclusion, Clare identified several key takeaways for researchers and advocates:

- **Policy change is not the sole measure of impact;** incremental shifts matter.
- **Policy intermediaries play a critical role** in translating research into action.
- **Accessibility is critical;** research behind paywalls limits policy uptake.
- **Clear, well-communicated messages** enhance influence.
- **Timing matters;** aligning findings with policy windows increases impact.
- **Alignment with stated governmental research priorities** can strengthen uptake.



Section 3: Communicating Research for Impact

Small group discussion findings

The roundtable discussions focused on how research can move beyond publication to achieve real-world impact for family carers. Unlike previous years, the emphasis was on building practical skills in identifying beneficiaries, tailoring communication, and strengthening pathways to impact. The session was facilitated by Dr Emma Dorris, Engaged Research Manager at UCD Research and Programme Manager with the PPI Ignite Network at University College Dublin.

Discussions centred on two structured tasks: identifying who needs to experience the impact of research and developing practical “impact recipes” to support translation into action.

Across groups, family carers were consistently identified as primary beneficiaries, with participants emphasising the diversity of caring roles and the importance of avoiding assumptions about a single, homogeneous “family” unit. Healthcare professionals, service providers, policymakers, educators, and advocacy organisations were identified as key secondary stakeholders whose engagement is essential to achieving impact. Participants stressed that carers should be recognised as stakeholders in their own right rather than positioned indirectly within professional systems.





In developing “impact recipes,” participants highlighted the need for tailored communication strategies for different audiences. Policymakers were seen as responding best to concise, actionable briefings, while healthcare professionals prioritised practical guidance and clinical relevance. Accessible formats were viewed as essential for engaging carers. Across tables, participants emphasised that academic outputs alone are insufficient; accessible formats, open access, and clear messaging are critical to uptake.

Barriers to impact included limited resources, competing policy priorities, fragmented systems, and weak coordination across sectors. Partnership working, particularly collaboration between researchers, FCI, carers, service providers, and policymakers, was repeatedly identified as central to translating evidence into change.

Emma concluded by emphasising that research impact requires intentional planning, sustained relationships and cross-sector collaboration. Achieving meaningful change for family carers depends on strategic engagement beyond academia.



Response and Reflections from Family Carers Ireland

Catherine Cox, Head of Communications and Policy, Family Carers Ireland

In her closing response, Catherine Cox reflected on the themes emerging from the roundtable discussions and the wider conference. She noted the consistency across tables in emphasising the importance of clear, simple and accessible communication.

She welcomed the suggestion of a “one-stop shop” for carers and reaffirmed FCI’s role in fulfilling this function. However, she acknowledged that awareness remains a significant challenge. Improving public understanding of who FCI is, what it does and how it supports carers continues to be a communications priority, alongside the need for adequate resourcing to respond effectively when carers seek support.



From a communications perspective, she pointed to the value of clear, headline statistics in influencing public and policy discourse. Referring to findings from the organisation’s State of Caring research, she noted that concise and memorable figures can powerfully convey the reality of caring and support advocacy efforts. Short, direct messages that “do what they say on the tin” were seen as especially effective in capturing attention and prompting engagement. Evidence that highlights not only the positive impact for carers but also efficiencies or improvements for the wider system can be particularly persuasive for policymakers and service managers. Showing that there is a “win” for both carers and the system strengthens the case for change.

Catherine stressed that carers must remain at the centre of all research and policy work. Echoing the principle of “nothing about you without you,” she underlined the importance of ensuring that carers are actively involved in shaping research, communications and policy development, rather than being treated as passive subjects.

She also reflected on innovative approaches discussed during the day, including the potential use of digital tools and artificial intelligence to improve access to information. In addition, she referenced the concept of a Carer Passport or carer registration model, such as that operating in the United Kingdom, as potential mechanisms for formally recognising carers within primary care settings and connecting them to supports in Ireland.

In closing, Catherine Cox thanked all contributors to the conference, with particular acknowledgement of the family carers who shared their experiences. She recognised the courage required to speak publicly about deeply personal and sometimes difficult issues and thanked participants for their engagement, noting that the discussions would inform FCI’s future work.



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