Family Carers Ireland

No one should have to care alone

Research Conference 2024

Partnership in Practice

4th Dec 2024, Ashling Hotel, Dublin.

HOSTED BY FAMILY CARERS IRELAND

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 its chair, Rob Anderson, who also skilfully chaired the conference. Family Carers Ireland is grateful to the conference speakers for sharing their knowledge and research findings as well as highlighting potential paths forward in research and policymaking. We appreciate the input 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.

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 Family Carers Ireland who shared their experiences of caring and the challenges and benefits of being involved in research.

Introduction and Conference Agenda

In its fourth year in 2024, the 'Partnership in Practice' conference is an annual event hosted by Family Carers Ireland designed to engage stakeholders on issues related to research on family caring. It involves family carers, researchers, health and social care practitioners, people from Government departments, statutory bodies and NGOs. It presents an opportunity for attendees to hear about findings from recent carer research, to work together to unpack some of the challenges involved and to explore the implications for policy and practice.

An advisory panel was convened by Family Carers Ireland consisting of family carers and academic and civil society representatives. Panel members co-developed the agenda for the day and the discussion group topics, aiming to devise an inclusive event with content that was useful and accessible to the range of people attending. The conference took place over a morning session where speakers presented research on caring, followed by a facilitated discussion session. The conference was attended by over 50 people.

THE CONFERENCE AGENDA INCLUDED:

1. **Guest Speakers**
   Presenting on research on caring, accompanied in each case by speakers who have been involved in related PPI processes as well as having experience of caring.

2. **Q&A Sessions**
   After each presentation.

3. **Roundtable Discussion**
   Small, mixed discussion groups to brainstorm on some key issues related to research on family caring whose recommendations were shared with the larger group.

Opening Remarks:

Dr Ann Leahy,
RESEARCH MANAGER, FAMILY CARERS IRELAND

This conference presents opportunities to hear about research that Family Carers Ireland has been involved in, and to contribute to discussions of that research, including the opportunity to contribute to strategic thinking about different ways in which Family Carers Ireland will work on research into the future.

Core to the day are the carers in the room, including members of the Public and Patient Involvement panel (PPI) at Family Carers Ireland, some of whom will be presenting about their experiences of being involved in research. We foreground PPI in today's proceedings because PPI is considered by Family Carers Ireland to be a central component of the way in which we approach our research work. This aligns with our commitment to placing carers at the heart of everything that we do. In addition, our approach is informed by the knowledge that when it is done well, PPI has much to contribute to research and that it can have a positive impact on all aspects of research. PPI can clearly influence and shape research, by, for example, introducing skills and perspectives that may not exist amongst the research team and potentially it can also challenge researcher biases. Alongside improving the quality and relevance of research, it can also promote a sense of empowerment among carers, and it can contribute to increased trust and acceptability of research findings in the carer community.

Message from **Damien Douglas,**

FAMILY CARER

The conference opening remarks concluded with a message from Damien Douglas, a family carer. Damien introduced himself as the father of identical twins, who live with a rare condition. He described the severe physical and intellectual disabilities they face emphasising also that, despite these challenges, they bring immense joy with their beautiful smiles and laughter. Damien outlined how he used to work as a psychiatric nurse in mental health services and contrasted that with the experience of being a family carer, where you lack the backup that you might have in a professional role. He outlined how his engagement with Family Carers Ireland started when his daughters reached 18 years of age and he had to give up work. Amongst the issues that Family Carers Ireland helped with was in getting access to a day service. In his experience, a carer's advocacy never stops. In this respect, a challenge is to communicate how you can be helped, and sometimes carers have to present the solutions. That is where research can play a crucial role. However, a challenge is to make the research meaningful to people on the ground who might benefit from it. Most carers will not read academic books or papers. But Damien gave an example of how participating in research can work. He outlined how he was a PPI contributor on research into a participation income for carers conducted at Maynooth University in partnership with Family Carers Ireland. He felt that a real effort was made to make the research meaningful to everyone. The information came from people on the ground and it was placed in the context of everyday life. Where research is of necessity quite complex, carers have the gift of helping researchers to make it meaningful and understandable to other carers.

SECTION 1:

Partnerships In Practice - Presentations

Christine Osswald


Joanne Murphy

Family Carers Ireland's State of Caring Report 2024

Joanne Murphy | Research Officer, Family Carers Ireland
Christine Osswald | Member of Family Carer Ireland's Public and Patient Involvement Panel

The State of Caring 2024 presentation provided a detailed examination of the realities faced by family carers across Ireland. Conducted by Family Carers Ireland between January 21st and March 5th 2024, the survey gathered responses from 2,127 family carers, with participants reached through both online and postal distribution of questionnaires. Most responses came from people who are members of Family Carers Ireland. Findings highlighted the significant challenges that carers experience daily, with 78% providing over 90 hours of care per week and nearly a third caring for multiple individuals. Most respondents were women (90%), the average age of those who participated was 49 years, and 68% reported that they were caring for a son or daughter.

UNMET NEEDS AND ACCESS TO FORMAL SUPPORTS

A striking 74% of the carers who participated in the study stated that the individuals they care for do not receive enough formal support, while 72% reported never having had access to respite care. Many families also face financial strain, with almost half having to pay privately for products or services that should be publicly available. Staffing shortages, lack of accessible services, and limited information often prevent carers from securing the support they need. In some cases, carers themselves are reluctant to seek help, unsure of where to turn, or concerned about the suitability of available options.

Access to respite care remains a significant challenge, with many carers struggling to find available, appropriate, or affordable options. Some face resistance from their loved ones, while others encounter barriers such as a lack of information, concerns over care quality, or the need for highly specialised support. When asked about their preferences, in-home respite was the most favoured option (28%), followed by overnight residential respite (20%) and day care respite (14%). However, accessing respite care remains a widespread problem.

CARER HEALTH AND WELL-BEING

The survey results painted a stark picture of the impact of caregiving on health and well-being. Only 4% of respondents described themselves as very or extremely satisfied with their lives, while nearly half reported some level of dissatisfaction. Loneliness emerged as a major concern, with 76% of carers experiencing moderate to severe loneliness, and those in poor health being the most affected. Many also reported having to sacrifice social connections due to financial pressures, with 32% cutting back on time with friends and family to make ends meet.

FINANCIAL STRUGGLES

Caring responsibilities often lead to financial distress, with 69% of the carers surveyed struggling to make ends meet. Among them, 29% reported cutting back on essentials such as food and heating, while 47% were reducing spending on social activities. Utility bills were another concern, with 16% of respondents struggling to keep up with payments. Many carers have also had to cut back on hobbies and non-essential expenses, highlighting the financial sacrifices they make in order to provide care.

HOUSING AND CARING

This year's special module focused on housing challenges for carers and the people they support. Many respondents faced difficulties in securing appropriate accommodation, with 34% stating that their home was not suitable to meet the needs of the person they care for. Financial difficulties were also a major issue, with 17% of mortgage holders and 35% of private renters missing a payment in the past year. Some carers had to rely on family and friends to fund necessary home adaptations, while others found that available grants only covered part of the costs. One in four of the carers who responded still require further home adaptations, underscoring the urgent need for better housing supports.

RECOMMENDATIONS FOR POLICY CHANGE

The presentation concluded with some recommendations aimed at improving the lives of family carers. Addressing housing challenges was a central focus. The report called for an increase in the maximum grant available under the Housing Adaptation Grant Scheme, as well as changes in the income thresholds applied. Other recommendations made include changes to the operation of the Differential Rent Scheme to take account of the substantial costs that carers face as a direct result of caring responsibilities. The report also emphasised the need for improved access to formal supports, including the introduction of a statutory home support scheme and efforts to tackle long waiting lists for essential therapies and assessments. Financial security was another major area identified for reform, with recommendations to abolish the means test for Carer's Allowance and to provide carers with an adequate income. Expanding eligibility for the Fuel Allowance was also suggested to help ease financial strain.

Beyond financial and housing concerns, the report also highlighted the need for access to targeted supports designed to tackle loneliness, as well as better opportunities for carers to stay in employment if they wish to do so. Additionally, ensuring a minimum of 20 days of guaranteed respite per year was identified as a crucial step in supporting carer well-being, alongside a national audit of respite facilities and the introduction of a national respite register.

Overall, the State of Caring 2024 survey paints a picture of immense challenges faced by family carers, from financial strain and inadequate formal support to long-term impacts on health and well-being. The findings underline the urgent need for policy reforms that will provide carers with the support, financial security, and recognition they deserve. Family Carers Ireland's recommendations offer a roadmap for change, emphasising the importance of accessible services, financial assistance, and practical supports to ensure that carers are no longer overlooked.

Christine Osswald, PPI representative

Christine Osswald, a PPI contributor and Family Carers Ireland PPI panel member, spoke about her experience of working with a student to further analyse the housing data. Christine spoke to her experience as a carer for her teenage son with Down syndrome and as a migrant carer. She responded to the presentation by reflecting on how the housing situation varies considerably depending on factors such as whether you own your own home or whether your situation requires physical adaptations, and highlighted how the additional needs of carers are often overlooked in housing policies. In relation to research, she found the experience of being a PPI contributor very interesting, as it can help counter how data can be presented in isolation from experiences in the real world or without seeing a bigger picture. She expressed the hope that her involvement in research would contribute to meaningful change.

Ray Lucey

Counting the Cost:

The Contribution of Older Carers in Ireland and Impact of Caring on Mental Health and Well-being of Carers: Evidence from The Irish Longitudinal Study on Ageing (TILDA)

Ray Lucey | Member of Family Carer Ireland's PPI Panel
Dr Christine McGarrigle | TILDA, Trinity College Dublin

Ray Lucey, PPI representative with the project

Ray Lucey commenced this presentation by talking about his time caring, followed by carer experiences that he became aware of due to attending events involving other carers, and his experience as a journalist writing about caring. His experience of caring for his mother, while simultaneously working and having to engage in long commutes and supporting his own family from a distance, led to starting to fight for his mother's rights. As a journalist, he was able to highlight issues impacting carers. He has come to believe that it is imperative that we have carers involved in research. Engagement with the Counting the Cost project was facilitated by the project team presenting the qualitative and quantitative data in language that was accessible to anyone and in a very user-friendly way. A highlight of the findings for Ray was seeing the impact of the relationship between the carer and the care recipient, whereby an issue affecting one of them (such as depression) also impacts on the other.

Dr Christine McGarrigle, TILDA, Trinity College Dublin

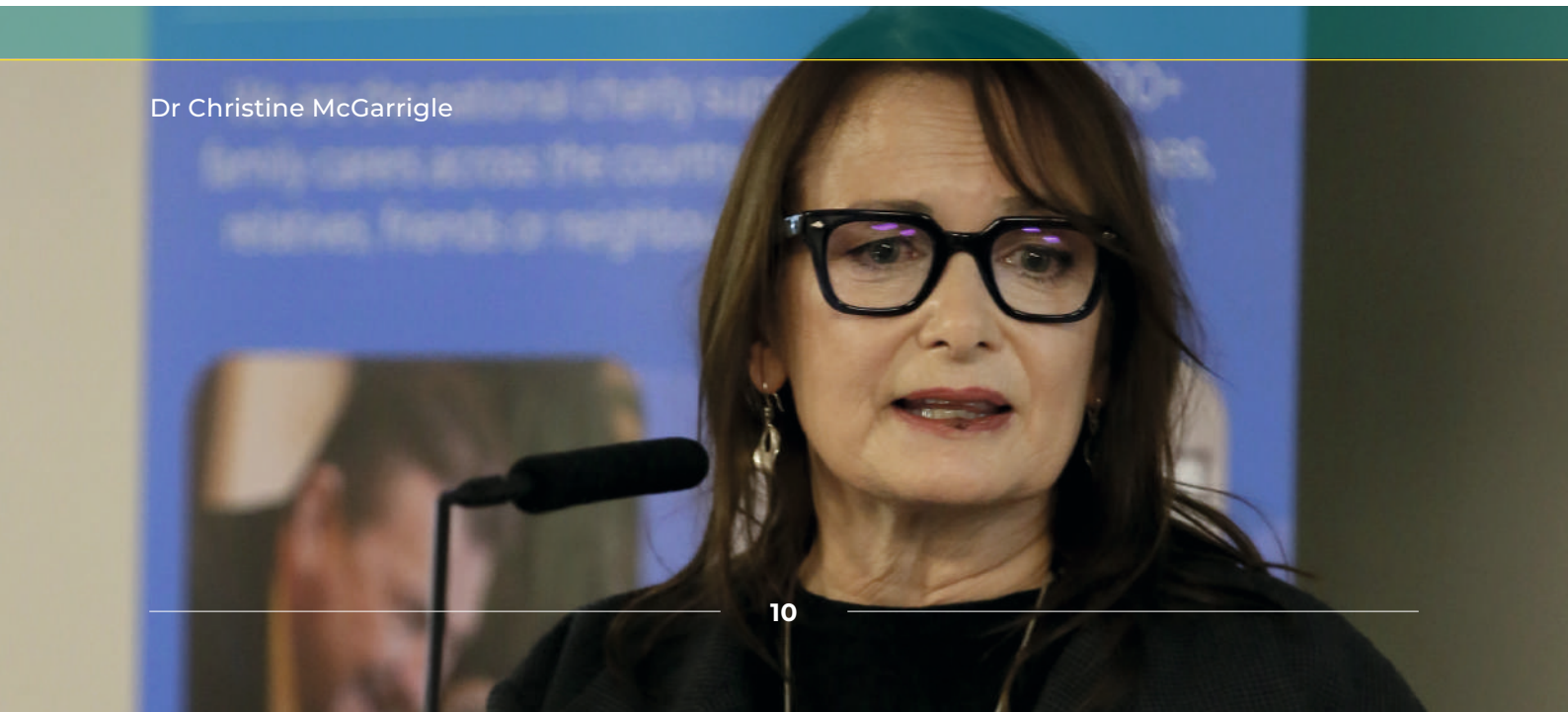
The Counting the Cost research explores the varying experiences and well-being of carers, emphasising the role of resilience in adapting to caregiving stress. The study used both quantitative data from the Irish Longitudinal Study on Ageing (TILDA) and qualitative data from focus groups with carers. The goal was to identify factors that support the psychosocial resilience of carers and their well-being.

It is clear that caring has an impact on carers, but what the study found is that the responses of carers, and the different outcomes for carers, may reflect different approaches or adaptability to caring. That is the reason for the focus on 'resilience', a process of negotiating, managing and adapting to significant cases of stress or trauma. In the first instance, the study uses quantitative data from TILDA, a nationally representative study of people in the country aged over 50. From that, it was possible to get a nationally representative sample of carers and to look at changes amongst them over time. The second component involved focus groups of carers.

One of the top-level findings from the quantitative study was that carers could be categorised as falling into three groups in terms of well-being over time. The first were resilient-stable - carers whose well-being remained the same after becoming caregivers. The next group could be categorised as resilient-recovery - carers whose well-being initially dropped but later recovered. The third group were categorised as non-resilient - carers whose well-being dropped and did not recover. Being in that non-resilient group was associated with caring for an adult child, higher educational levels, having chronic conditions, or having depressive symptoms. The resilient group was associated with social integration. The higher your social integration, the more likely you were to be in that resilient group, and particularly important was the number of close friends and relatives you had.

Using Actor-Partner Interdependence Models, the research found that depressive symptoms in either the carer or the care recipient negatively impacted the quality of life for both. However, higher social integration of the carer was protective, lessening the impact of depressive symptoms on both the carer and care recipient. This demonstrates that if you look after the carer's health, you will also look after the health of the care recipient. And the same is true for the recipient and the carer. This is independent of everything else and it is an important finding in a nationally representative sample.

The second part of the study involved focus groups, working in collaboration with Family Carers Ireland to recruit middle-aged and older adults who were caring. Two focus groups took place, one in Cork and one in Dublin, with 20 participants in total (16 women and four men, age range 47–77 years). They represented different kinds of caring experiences – caring for a spouse, children, parents, or a friend. The topics were developed with the PPI group and were intended to explore those differences and similarities in meanings related to resilience and thinking about those supportive factors for resilience.



Dr Christine McGarrigle

Analysis of the focus groups' discussions resulted in identifying nine key themes:

1.
Fighting:

The stress of caregiving was sometimes described as a "fight," both an ongoing struggle with the system and a source of resilience for some

2.
Loneliness and Isolation:

Some carers felt profound loneliness even if they were personally sociable.

3.
Relationship Breakdown:

Issues arising in relationships were associated with caring, and breakdown in relationships also overlapped with the issue of financial poverty.

4.
Worries:

There were day-to-day worries about support and care for their loved ones and about the future, including what would happen when they were gone.

5.
Self-care and Respite:

This was discussed in the context of depending heavily on the supports that were available. Related to that was the availability of family support and finances. Something that emerged quite strongly was that counselling could be very important, with people using both Family Carers Ireland's counselling support and engaging with its support groups. People were looking for the right kind of support group and that changed with time.

6.
Guilt:

Carers expressed guilt over divided attention between their own families and the person they cared for.

7.
Gendered Roles:

Gender played a role in both caregiving and in accessing support groups - with a man reporting challenges in engaging with members of support groups that were mainly female.

8.
Burnout and Recovery:

Many carers faced exhaustion and mental stress but found mechanisms of recovery.

9.
Poverty:

Financial difficulties were prevalent, with carers sometimes giving up work to provide care, leading to financial strain, and limiting opportunities for their families. Relationship breakup sometimes contributed to this.

The study demonstrates quite strongly that one partner's depressive symptoms also affect an individual's quality of life. This is the case for both carers and care recipients. Social integration improves not only the well-being of the carer but also the well-being of the care recipient. The voices of carers were consistent, although needs varied depending on their position in their caring journey. It is important to recognise the complex nature of the caregiving relationship, and that it changes over time. That has to be taken into consideration when we are thinking about what is best or what supports can best fit into a caregiver's life.

This study was funded through Health Research Charities Ireland, co-funded by Family Carers Ireland and the Health Research Board.

PPI-POWER:

Planning Our Work with Equity and Respect

Dr. Anne-Marie Martin | School of Nursing and Midwifery, University College Cork
Lorraine Woods | Member of Family Carer Ireland's PPI Panel.

PPI-POWER (Public and Patient Involvement – Planning Our Work with Equity and Respect) is a seed project focused on documenting how research can be conducted collaboratively with people who have direct experience of the topic. It is focused on people at risk of being excluded from PPI, namely people with severe or profound intellectual disability. The team consists of a researcher and three PPI partners – Kayleigh Twomey, Mary Doyle Kent, and Lorraine Woods, one of whom has an intellectual disability and two of whom are parents of individuals with profound intellectual disabilities. Additionally, the research officer of Family Carers Ireland also contributed. Together, they set project aims: to document both the benefits and challenges of PPI, outline strategies that support its success, and establish research priorities for a future grant application. An application to the PPI Ignite @ UCC seed funding scheme was successful and enabled the work to progress. Over 12 months, the partners met approximately every six weeks, and used a diary study approach, recording how they worked together, including how the partnership was built. They met largely online, although there were also some individual meetings. One person preferred one-one-one meetings with the researcher because it helped with communication. At the end of the year, they have established a PPI partnership, developed a paper together, and identified research priorities in preparation for a larger grant application.

The processes pursued were informed by the values and principles framework from the PPI Ignite network, which was also used to structure a paper written by the team. The principle of **respect** involved recognising the roles, knowledge, experiences, and contributions across the research team. The groundwork for 'respect' was set by discussing why each team member wanted to be involved, including acknowledgement of what research can offer and what it cannot do. Respect helps **trust** to develop, which requires knowing that no one will be judged for their contributions. Additionally, while participants needed to be able to rely on each other, it was also acknowledged that this project was only part of anyone's life and circumstances could change. Therefore, there had to be **flexibility** and acknowledgement of commitments that each person had outside of the project. **Transparency** was demonstrated by holding the first meeting before applying for funding and sharing meeting notes among the whole group so that everyone was aware of what was discussed.

Empowerment and power sharing meant inclusion of PPI contributors in all decisions, in the strategy and the co-design. Starting with PPI meant that goals identified were relevant to all the participants. As regards **equity and inclusion**, this involves the active identification and removal of barriers and valuing equally people's diverse inputs. An example of this is how the group wrote a paper together. A plan was agreed for the paper, including points that each contributor wanted to make. The work was divided, and it was written in an accessible format and included everyone's contribution. **Collaboration and partnership** are central to the whole process, and the seed funding was crucial in providing the necessary time and resources to establish a strong, meaningful partnership.

Key recommendations for future PPI research:

1. Integrate PPI partners from the start to ensure research is relevant and valuable.
2. For bigger projects, appoint a dedicated team member to support PPI participation.
3. Reserve meeting time specifically for PPI partners to share their perspectives.
4. Ensure funding is available to support PPI collaborations effectively.

PPI-POWER demonstrates how research can be made more inclusive and impactful through meaningful collaboration and it serves as a model for future PPI initiatives, encouraging more involvement from people with intellectual disabilities and their families.

Lorraine Woods

Lorraine Woods, PPI representative with the project

Lorraine Woods, a mother and full-time carer, shared her experience of participating in the PPI-POWER project. Lorraine cares for her adult daughter who has a rare degenerative genetic disorder and requires round-the-clock care.

Her key reflections included:

- Bringing a Unique Perspective: Experience as a full-time carer provided insight into the realities faced by families.
- Feeling Valued in Research: The collaborative environment created by Dr. Anne-Marie Martin and the other participants made her feel respected, empowered, and encouraged to share her experiences.
- Breaking Barriers: Despite having no prior experience of working with researchers or policymakers, Lorraine found that her contributions were acknowledged and genuinely appreciated.
- Advocacy Challenges: Being a carer can feel like a never-ending battle, and carers often struggle to find time to advocate for themselves while managing their responsibilities. However, being part of this research reassured Lorraine that their needs were being prioritised by dedicated professionals.

She feels confident that the research that will emerge will put the experiences of carers and people with profound intellectual disabilities to the fore. Like that of all the PPI contributors at the conference, Lorraine's involvement in the research highlights the importance of including carers in research. Their lived experiences provide insights that can shape policies and improve access to resources for families with complex needs.

This project was funded by the PPI Ignite @ UCC - PPI Seed Funding Scheme.

SECTION 2:

Roundtable Discussion on a Strategic Approach to Research for Family Carers Ireland

The purpose of the roundtable discussions was to start considering a strategic approach to research within Family Carers Ireland, given the context of having a small research team and needing to make decisions as to what to prioritise. In particular, the discussion aimed to elicit the views of participants in respect of two areas – the role of research in contributing to the overall vision of Family Carers Ireland, and the principal areas for research on which the organisation should focus. This part of the conference was facilitated by Dr Emma Dorris from PPI Ignite, University College Dublin. Group discussion took place at six tables, each of which had a volunteer facilitator assigned to guide the discussion and to provide feedback to the larger group. Participants were encouraged to write down their individual ideas before sharing them with others around their tables, and they were also given the opportunity to contribute individual points that they felt needed to be added to the feedback from table facilitators.

The sections that follow combine the key points that were fed back on the two tasks that were assigned - the first relating to a vision for a research strategy and the second relating to what areas should be prioritised for research by Family Carers Ireland. There was considerable overlap between feedback from the table facilitators, and some additional points were also contributed to the overall discussion by participants from their tables.

Task 1:

Vision for the Research of Family Carers Ireland – Recognition, Support and Empowerment

Task 1 started from the vision of Family Carers Ireland itself, which was presented as follows:

'OUR VISION IS AN IRELAND IN WHICH FAMILY CARERS AND YOUNG CARERS ARE PROPERLY RECOGNISED, SUPPORTED AND EMPOWERED'

Participants were asked to discuss how research could contribute to the overall vision of Family Carers Ireland and, in particular, to carers being recognised, supported and empowered, and facilitators were asked to give feedback under those three headings. Thus, the question posed was how can research:

- **Promote recognition** of family carers?
- **Improve support** structures for family carers?
- **Empower** family carers?

Most of the suggestions that were contributed were grouped under the heading of 'recognition' but there were also some contributions under the other two headings.

PROMOTE RECOGNITION

There was considerable overlap and agreement amongst participants at different tables on the key issues identified in relation to the contribution of research to the recognition of caring. Key points made concerned how research can contribute to raising awareness and to 'making the invisible visible', and thereby to the recognition of family carers by highlighting the work of caring and its value. This in turn was perceived to contribute to change in perceptions of carers, including by presenting statistics and by foregrounding the voice of family carers, all of which make the situation of carers better known and understood. Increased awareness associated with research was perceived to help to influence policymaking. Communication of research findings – to carers and others – was highlighted as key to awareness and recognition.

Linked to the issue of awareness-raising were suggestions that research can help to promote recognition of different aspects of caring. Underlined in this regard was the intensity of the caring experience for many, which is not always well understood. Also mentioned were less recognised or understood groups of carers – such as carers who are migrants (who it was felt can experience greater isolation as they may not be as well integrated as others) or who belong to other groups like Travellers.

IMPROVE SUPPORT STRUCTURES

Turning to the issue of 'support structures', a key point discussed in the context of research concerned its usefulness in work to influence policymaking, including by presenting evaluations of existing supports. Thus, it was stated that, by putting concrete examples out in public, research could support structural change. Relatedly, it was argued that by identifying inadequate supports, research enhances empowerment in terms of informing advocacy and evidence-based policymaking.

A point was also contributed that research cannot do everything – it has to be meaningful research, but even then, it does not always translate into policy or improved supports on the ground. Also referred to in the context of support was the need for a mentorship programme and supporting carers through assisted decision-making processes.

EMPOWER FAMILY CARERS

The recognition aspect of research was linked to the empowerment of carers, to greater self-identification as carers, and to greater appreciation of carer contributions. By highlighting themes and experiences that are common to many carers, it was felt that research can validate individual experiences. Relatedly, it was argued that research identifying inadequate supports enhances empowerment in terms of informing advocacy and evidence-based policymaking and that candid conversations with healthcare professionals can help address their reticence in engaging with family carers – all of which was felt to build confidence and empowerment of family carers.

Linked to the idea of empowerment was the suggestion that carers need to be partners in research processes with a role and an opportunity to give back. It was also suggested that Family Carers Ireland needs to support PPI and to make sure it is not tokenistic and try to hold researchers accountable for their PPI processes.

Task 2:

Potential Areas to Prioritise in Research

The second task focused on potential areas for research on which Family Carers Ireland could focus. Thus, participants were asked to identify broad research areas of potential interest for Family Carers Ireland. There was considerable diversity in the feedback received, but it is possible to group the contributions into six main areas.

Before outlining the six areas, it is also worth noting that some points were made about the role of Family Carers Ireland in research and of the need for reflection on the role that the organisation can play in the broader research environment in Ireland. Related to that was the suggestion of the need to take stock of existing evidence and how it can be used to advocate, since Family Carers Ireland has a small research team, does not always have to be involved in new research, and could focus more on translating existing knowledge into impact or solutions.

Specific areas identified as potential areas of research focus can be grouped as follows:

1. Lifespan or long-term approaches:

A number of different suggestions were made relating to research focused on caring over time, which was considered necessary to foster responses to the needs of carers and people they care for that change in the long term. Suggestions included research on Assessments of Need that take account of both the short and long term in relation to homes and adaptations, and also including a research focus on transition points such as ages 18 and 65+. Linked to this was the need to anticipate housing adaptations and to foster a universal approach to design that can respond to the fact that everyone is ageing.

Connected with long-term issues was a suggestion of the need for research with siblings who care over the long term and also the need for research with people with disabilities who take on caring roles for their parents or carers as they age.

2. Service evaluation and intervention studies:

Several contributors stressed evaluation and intervention studies and, relatedly, referenced the need for research focused on solutions to issues. This was linked to the need to try and use evidence to influence policymaking and to demonstrate efficacy of various programmes – especially in home care – and to make clear the real-world implications of policy decisions. In that connection, comparisons with other countries (including north/south comparisons in Ireland) were highlighted in an effort to focus on solutions and ascertain what can usefully be learned about supportive models. One participant suggested that research could scope out whether there is the need for new services such as emergency response for out-of-hours and weekend needs. An additional point was made about the need to normalise disability awareness within schools and other centres and hence to challenge attitudes about disability, with a suggestion that there are some existing models that could be highlighted as best practice examples.

3. Grief and loss that goes with caring:

Some participants focused on grief and the physical and emotional cost of caring, which can sometimes be associated with guilt or anger, and the impact of these issues on relationships.

4. Loneliness:

Social and structural determinants of loneliness were discussed and how loneliness is contributed to through lack of access to services.

5. Economic issues and cost-benefit analysis:

Economic analysis related to caring was highlighted as a possible area of focus. Somewhat linked to that was a reference to the financial cost of caring to carers, the administrative burden of navigating the care system, and what proportion of Carer's Allowance is spent on supporting the requirements of the person receiving care and, thus, on subsidising deficits in health and social care provision.

6. Impact of caring on different groups:

Several participants referred to the need to focus on groups of carers whose experiences are not well known, amongst whom young carers were highlighted, along with carers from different backgrounds, including Travellers and migrants. A point was also made about former carers - and whether Family Carers Ireland could use their lived experience more through mentoring.

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No one should have to care alone

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