

Scottish Universities Insight Institute project



From competition to collaboration: the interface between informal and formal carers

Partner country profile: Ireland

Context

Carer Policy

In Ireland, carers are supported through financial and other supports for family carers and health-related home and community services. These policies are designed to assist carers in managing their responsibilities and to provide financial support, respite, and other services¹.

Implementation of Financial and Employment Supports:

1. **Long-Term Carers Contribution Pension Scheme:** One of the most significant policy changes in Ireland recently is an enhanced State Pension provision for long-term carers introduced from January 2024. If you have been a full-time carer for at least 20 years (1040 weeks), you can get Long-Term Carers Contributions to help you qualify for the State Pension (Contributory). This reform represents an important acknowledgement of the invaluable role family carers play in Irish society.
2. **Carer's Allowance:** This is a means-tested payment for full-time family carers.
3. **Carer's Benefit:** Unlike Carer's Allowance, Carer's Benefit is not means-tested but is based on the carer's PRSI contributions. It's paid to individuals who leave the workforce temporarily to care for a person(s) in need of full-time care and attention.
4. **Carer's Leave:** This provision allows employees to take unpaid leave from their jobs to provide full-time care for someone for a period of up to 104 weeks. This leave is protected, meaning carers have the right to return to their job after the leave period.
5. **Domiciliary Care Allowance (DCA):** DCA is a monthly payment for a child under 16 with a severe disability, who requires ongoing care and attention, substantially over and above what is usually required by a child the same age. It is not means tested. The guidelines state that the payment is not based on the type of disability but on the physical or mental impairment.
6. **Tax relief and Credits:** As well as direct payments, Ireland has a range of tax reliefs and tax credits available to caring families. The Home Carer's Tax Credit is given to married couples or civil partners (jointly assessed for tax) where one partner works in the home caring for a dependent person. This person can be a child, an adult over 66 years or a person with a disability who requires care. The conditions are much less stringent as compared with specific provisions for carers' benefits.
7. **General Social Welfare Benefits:** Carers may also be eligible for other social welfare benefits depending on circumstances, such as the Household Benefits Package, which includes allowances towards the cost of electricity, gas, or telephone rental.

¹ <https://eurocarers.org/country-profiles/ireland/>

Barriers to implementing financial supports:

Carer's Allowance is a means tested, taxable weekly payment, much like other working aged social assistance payments. Rather than a payment that socially values care, it is understood as an antipoverty measure. The means test impacts in multiple ways: the payment is inaccessible to many and inadequate for most, with significant restrictions that limit capacity to advance in life, discouraging labour market participation due to an 18.5 hour ceiling on work/study. It also reinforces gender stereotypes of women as primary caregivers – means testing on partners' income leaves many women financially dependent on men. In summary, there are growing concerns about coverage, adequacy and impact on paid labour market participation². The means test is a significant barrier to the financial wellbeing of carers.

Implementation of Practical Supports

1. **Right to nursing home care:** When it comes to the provision of formal care to older persons, the only statutory scheme currently in place is for residential long-term care which is accessed and funded through the Nursing Home Support Scheme administered by the HSE (commonly referred to as 'Fair Deal').
2. **Home care:** Whilst older people have a 'right' to nursing home care under the statutory provisions of 'Fair Deal', there is no equal right to home care – which is discretionary. Although the Irish Government has committed to addressing this anomaly through a Statutory Home Care Scheme, this has not yet commenced. The scheme, to include adults of all ages, aims to ensure that users of home support services are provided with a standard, high-quality level of care which is safe, effective and person-centred. Work on the development of a statutory home support scheme commenced in 2017 and was due to commence in 2021. Given the current delays, it is unlikely the scheme will be introduced before 2025.
3. **Respite Care:** The Irish Health Service Executive (HSE) provides respite care to give carers a rest from caregiving responsibilities. This can be arranged through local health offices and can take the form of in-home respite care, day care, or overnight respite. However, the availability of residential respite has come under pressure in recent years due to factors including increased demand, the need for specialist respite for children and adults with complex care needs and HIQA regulations.
4. **National Carers' Strategy:** Initiated in 2012, Ireland's first National Carer's Strategy outlined the government's commitment to recognising and supporting carers. It focused on ensuring that carers are supported financially, socially, and health-wise, and that they are empowered to participate fully in economic and social life. Whilst the Department of Health agreed in 2019 that the actions contained in the first strategy were exhausted and a refreshed Strategy committed to in 2020, the new strategy has not yet materialised.
5. **Training and Information:** The HSE and various non-profit organizations including Family Carers Ireland offer training and education for carers; covering topics like manual handling, basic first aid, and the management of specific medical conditions.

Barriers to implementing practical supports:

The main barriers to implementing practical supports include under-resourcing, difficulty in delivering services due to staff shortages and the postcode lottery. For example, the Irish

² MacMahon et al, 2022; Murphy et al, 2023

Government first committed to the introduction of a Statutory Home Support Scheme in January 2017 with the subsequent Sláintecare Implementation Strategy, published in 2018, targeting the passing of legislation for statutory home care by 2021. While the importance of the scheme has been amplified by the pandemic, the crisis has also caused its delay, with the scheme now unlikely before 2025. While this delay is understandable, the ongoing recruitment and retention crisis within the home care sector is a significant problem. Moreover, inconsistent funding across the country means access to essential supports such as respite and home care packages is subject to a postcode lottery, whereby where a person lives, rather than their need will determine if they can access a service or not.

What could help?

To enhance collaboration between professional carers and family carers in Ireland requires thinking beyond the traditional care dyad into a more integrated triad. Several strategies can be considered to better respect and include carers as partners in the caregiving process:

1. **Statutory Homecare Scheme:** The legislative gap between a person's right to nursing home care and the discretionary basis for home support is long-standing, having been created with the introduction of the Nursing Home Support Scheme (Fair Deal) in 2009. During these 14 years, families have had to accept a system that incentivises residential care and spends twice as much on Fair Deal than on home care, despite Government policy to support care at home. The establishment of the scheme should be given utmost priority with an agreed timeline towards its introduction and appropriate funding made available to meet the demand implications. It is also dependent on having access to a skilled pool of workers across the country. Even before the scheme is launched, the acute shortage of workers is having a detrimental effect on the sector, with urgent efforts needed to promote employment and attract and retain workers in the home care sector.
2. **Refreshed National Carer's Strategy:** Given the current period of significant health reform, including the focus on Sláintecare and the creation of a statutory home support scheme (both of which are dependent on the support of family carers), as well as demographic change, healthcare advances, long-term care policy and cost-containment pressures, it is critical that a refreshed National Carers' Strategy and action plan are developed and funding is ringfenced for its delivery.
3. **Support Systems for Carers:** Recognising the emotional and physical toll on family carers is essential. Access to adequate, quality, appropriate and accessible supports such as respite care, counselling, and services for the people they care for can maintain carer wellbeing, enabling them to be more effective partners in caregiving.
4. **Education, training Regular Communication:** Providing joint training sessions for both professional and informal carers can foster mutual understanding and respect. These sessions can educate about each other's roles, challenges, and contributions, ensuring that both parties understand how to best support the care recipient and each other. Establishing consistent and structured communication channels between professional and informal carers is crucial. This might include regular meetings or updates to discuss the care recipient's progress, changes in health status, and any adjustments needed in the care plan. Digital tools like shared online platforms can facilitate real-time updates and feedback.

Workshop one (October 2023) Researcher

I just have one slide. A quick story about Niamh Ryan who is a carer for her two able bodied children and her child Liam who has a life limiting condition requiring full time care. She gave up her job to do that round the clock care. Ireland is seen as having a generous social welfare system. But despite the care Niamh provides to Liam and the expenses faced due to disability, Niamh receives very little financial support from the state. In Ireland we have a means test to be eligible for carers' allowance, which is the state income support. The means test means that regardless of hours of care, Niamh only gets 20 euro a week, and that is because her husband earns over the income disregard. So Niamh is financially dependent on her husband, the family financially struggle and she feels the care she provides isn't valued by the state. In Ireland we have calculated that one in four full time family carers receive carers allowance despite providing full time care.

My org recognise this as a growing concern. We commissioned Maynooth University last year to co-develop an income support reform. We did interviews with carers, a literature review, policy analysis and brought that together in a workshop with stakeholders to discuss the findings. The researchers developed the idea of a **participation income for carers. It is on the spectrum of a UBI but you have to do something socially valuable.** Lots of work would come under that, but we have looked at it in relation to carers specifically. We examined whether it was feasible and it is. It is not astronomical in cost, it socially values family carers. It fits in with what we have going on in Ireland. It is a bit of a step change but has been picked up by politicians. They recognise that we need to abolish the means test and this is a way of socially valuing care.

Workshop two (December 2023) Unpaid carer

I'm Sinead from Ireland, and I have my son Daniel, who is 16. We have had many carers since Daniel was 5, with many magic and tragic moments. But in the last while I would talk about the most magic carer I've ever had; Bhuto, from the Congo. Like others have said, we have this ethos as a family that we want to get to know every carer that comes in, and to trust them. We do speak about having care plans, and they're set down because they must be from the private companies. But I call them our guidelines, because the way I spoke with Bhuto is that you need to get to know, Daniel, and build your own relationship with him.

But what I noticed with Daniel this time was that he's so connected with Bhuto. We only have Bhuto 8 hours a week, over 3 afternoons, after school. Normally Daniel would have a meltdown after school but with Bhuto there he laughs, he smiles, he engages. Daniel vocalizes and Bhuto vocalizes every sound back to Daniel and that made Daniel feel that he was respected. It is important to have that friendship with Bhuto, separate from me.

Dan is quite well known in the community, and Bhuto brings him out for a walk. People in the community tell me of the great relationship that Daniel has with him. They see him laughing and smiling. Bhuto has taught Daniel how to hold his own spoon how to feed himself. Dan uses a wheelchair but when Bhuto takes him out, he sits him on one of the big chairs, makes him feel that he's just like anyone else. They take videos. They share every video moment with me and I save them and use them when Dan is having a meltdown.

I would have had guilt before with having carers. I've stopped having that guilt because Dan is getting to have all those experiences and enjoy life. You know my mum would often say to me, do you not mind having these people in your house? I would say, mam, anything for Dan to be happy, and to give me time to breathe and have space and moments to myself.

Workshop three (February 2024) Senior social worker

So my magic moment, I suppose, relates to a lady I met recently. So I'm a social worker, senior social worker, working in older adult mental health and although I've worked in with carers, probably for most of my career last 25 years, I thought that my most recent contact and showed why I really, I really still really love my job as a social worker.

So I was given a referral by my multidisciplinary team to provide support to the wife of a service user. And fairly recently we had a diagnosis of dementia. And so I tried to contact. I'm going to call her Claire, by phone both to her landline and her mobile with no success over a few weeks. So I went old school and thought, I'm not just gonna write to her and invite her to explain, I suppose my role and invite her to contact me. If she would like to meet with me, or to talk with me in terms of what support I could give to her. So she did contact me, following my letter, and we arranged to meet at a local coffee shop between Christmas and New Year this year.

Suppose, when we met, Claire said that receiving my letter had given her hope that somebody cared. And I suppose for me this stood out as a magic moment, that something so small in my mind actually meant so much to her. So in the course of our meeting I gave her a new kind of carer's assessment of need form that we're trialling within our team so she took it took it away with her, and later reported that she initially completed the form and could and it could identify few needs, really, but that she returned to doing the form a few days, or maybe a week later, whatever, and substantially changed. This form changed her answers as she kind of realised that she is both in need of and entitled to support in her role as caring for her husband. So again for me, that was another kind of magic moment I felt. So sort of tragic moments which I saw. Whatever was in the guilt she expressed about talking about her husband, and the difficulty finds in finding any space for her, for herself as he doesn't like to be left alone, or for her to go out without him and her.

She spoke about their, I suppose, changing relationships, and how to navigate this, and they both met as students in the field of engineering. So Claire noted, she found especially hard that there isn't a flow chart for what's happening now. There isn't a system to get through this current experience. So again, I suppose it's my hope that ongoing support with her will assist her in finding some kind of understanding, and how to continue to care for herself without losing her own personhood in this. And even since then she's been back in contact by email and wanting to meet up again. So I suppose there's elements of magic and tragic in that beautiful and often in small things, isn't it? So? Yeah.

Workshop four (August 2024) Senior Civil Servant, Department of Health

This story was shared by a senior civil servant in Ireland who thought it was a good example of policy because it was a formal collaboration between family carers, formal carers, the

Department of health, our health service, and NGOs, like ourselves, Family Carers Ireland. So the Department helped launch the pilot rollout of the Inter-RAI family carer and needs assessment in 2021 to 2023. The inter-RAI tools are comprehensive, standardised tools that evaluate the needs of various populations. This one was specific to carers. The project then provided tailored supports and services to different care groups' assessed outcomes, and then looked at the efficacy of the tool from the perspective of healthcare professionals. So in terms of the findings, the assessment identified the highest demands amongst carers, so identified that they needed respite, counselling and education. It also identified the needs of people with additional care needs. So they were mobility aids and home support and personal assistant hours. Professionals highly valued the information and said it gave them a holistic view. However, they were frustrated that the supports and services identified in the assessment form weren't actually available to deliver.

So there were magic and tragic moments but from my reflections I agree that it was a good example of collaboration. And for carers, it was the first time that their needs were formally recognised. It's the first time that they were asked, "How are you? What do you need in the Irish context?" Because we don't have any kind of right to a care and needs assessment at the moment. And it has tested referral pathways too, with most carers referred to us at Family Carers Ireland, because the Department didn't necessarily have the expertise or the supports available.

In terms of the tragic, the assessment tool isn't perfect, as many aren't, and the healthcare professionals who were asked about it found the form difficult, repetitive, and confusing, and it's paper based, as much still is in Ireland. And if we are to think about what's magical, it's the collaboration that's being established, and, for the first time, like an assessment tool in Ireland, rolled out by the Department of Health to see what carers needs are, and in their own right, and for us to be recognised as an organization that can deliver tailored supports to carers based on their own needs.