

Scottish Universities Insight Institute project



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

Partner country profile: Portugal

Context

Carer Policy

The Portuguese Informal Carers Statutes, regulating the rights and duties of carers and the cared for person, was approved in 2019 (Law nº. 100/2019, 6th September). This Law was supported by Portuguese Health and Social Ministry Working Group which produced a document: “*Medidas de Intervenção Junto dos Cuidadores Informais*”, (Intervention Measures for Informal Carers) integrating European practices inspired by Eurocarers and suggested by Associação Cuidadores de Portugal, the Working Group and others.

In this Law several rights are recognized if the carer is:

- **The principal informal carer** (Living with the person being cared for in the same house; providing care on a permanent basis; Not engage in paid professional activity; Not receiving unemployment benefits; Not receiving remuneration for the care provided)
- **Not principal informal carer** (regular, but not permanent basis, and may or may not receive remuneration for professional activity or for the care provided).

What are the conditions for being a cared for person?

For the purposes of recognising the status of informal caregiver, the person being cared for must meet the following conditions:

- Being dependent on others and needing permanent care; Not being accommodated in a social or health response, public or private, in a residential regime; Receive one of the following social benefits defined after a specific assessment by the Disability Verification Services of the Social Security Institute.

The informal caregiver, **duly recognised, has various rights** including:

- **Recognition** of their fundamental role in the performance and maintenance of the well-being of the person being cared for
- **Receive information and training** to develop their capabilities and acquire skills to provide adequate healthcare to the person being cared for
- Enjoy **psychological support** from health services, whenever necessary, even after the death of the person being cared for
- Benefit from **periods of rest** aimed at your well-being and emotional balance
- **Be supported to continue to work or study**
- **Have a voice** in defining public policies aimed at informal caregivers.

In the case of a **principal informal carer**, carers also have the right to:

- Receive **the Main Informal Carer Support Subsidy** , if meeting award conditions
- Request inclusion in the voluntary **Social Security Scheme**
- **integration into the labor market**, when the caring role ends.

Non-principal carers have the right to certain conditions, including telework for up to 4 years, where appropriate and the employer has resources to facilitate it; five working days leave a year; part-time and flexible work; exemption from additional work and 15 days leave a year for mandatory assistance (Law 13/2023, 3rd April)

Support measures for informal Carers (Regulatory Decree No. 1/2022, 10th January)

- Reference health and social security professional (mobilise available resources, in an integrated way, to respond to health and social support needs)
- Carers-specific intervention plan
- Self-help groups
- Training and information
- Psychosocial support
- Informal Caregiver Breaks (up to 30 days per year)
- Promoting integration into the labor market including recognition, validation and certification of skills.

Implementation

The Portuguese context of supporting promotion and recognition of caregivers has evolved in recent years, with the introduction of significant legislation. However, the pandemic and demographic pressure on the national health and social service shows the need for structural reform necessary to better meet the needs of the population.

Currently, despite promising legislation, many needs of carers are not met. Teams are overloaded with work and are not given the resources to implement the measures. For most carers, there is insufficient support for their wellbeing.

The criteria for being recognised as a primary carer and thus receiving more benefits are very strict with application limited to the poorest, who do not necessarily obtain access.

What could help?

- More integration responses between health and social care systems.
- Investment in innovative solutions and sharing good experiences in the field.
- Continuing monitoring the implementation of the carers legal recognition and open the criteria to support higher number of carers.
- Facilitate access to health and psychological support, special in isolated areas
- Promote resources for teams and contractualisation of services aiming support informal carers.

- Overcome difficulties related to bureaucracy in procedures.

Stories from Portugal

Workshop one (October 2023) Researcher

I want to share two stories of Portuguese carers, both women. First, Anna who lives near Porto, a coastal urban area and Maria who lives in the North in an isolated village. Both care for their mother with dementia. Anna has been supported with a course to deal better with dementia and for herself to feel better in her caring role. Maria however in the North didn't have any kind of training or collaboration. She is isolated and after a recent hip replacement does not feel able to care for her mother. Maria was not expecting to have to take so much care. Meanwhile she wants to find residential care for her mother but has had no responses.

In Portugal we have recent legislation which is a little based on the Scottish Carers Act where carers have the right to education and to support and to be involved in a plan for the cared for person. But the truth is that most of the formal carers don't know how to do this and struggle for time. We have noticed that in communities where there are alliances between city councils and third sector, health professionals invest their knowledge. Where there is leadership and also integrated care, we have better quality of collaboration between informal and formal care. Our thesis is that if we invest in these fields we can really change the quality of collaboration between formal and informal care – putting the carers in the centre of the system, which they are not in the moment.

Workshop three (February 2024) Nurse

My name is Anabela and I am a nurse for 28 years. I participate in this project with young carers. We also have a partnership with the social innovation program here from European community. Isolation is often the biggest situation for our families, it is the common denominator.

This is Dina and her father is a diabetic, and he's a fisherman working at sea. It was very interesting to see the potential of technology being used in this family. We had several health education sessions via Google meets with the whole family, in which each issue such as diet, exercise, health and choice was discussed. We ended up making a great friendship. Halfway through the sessions, and from that friendship we had formed, came an opportunity from this family, as a way of thanking us for these sessions, which was an invitation to watch one of the most fantastic fireworks I have ever seen in our city from their home. This was wonderful. Technology is wonderful. We can make his life better using this Internet. That is what we are using now.

Workshop four (April 2024) Cuidadores Portugal Coordinator

I have worked alongside the Portuguese government these past five years to develop legislation for informal carers. Now we have the legislation and the next step is implementation. The government created a committee of a lot of people in health and social care, also our association and other associations of carers to have their voice

heard in this process. But covid happened and the pressure was to focus elsewhere in health and social care. But the carer organisations continued to advocate for implementation and at the same time last year we had the new EU care strategy which included a focus on reconciling work and care. We do have in our policy a range of rights to flexible working, to teleworking and to days for mandatory assistance for informal carers. And we are learning that we have to make compromises along the way. And this is a story of my colleague Anna, who interviewed some politicians and practitioners and she says:

Health professionals were required to carry out yet another task, another task for them to do. And there are real challenges with the conciliation between health professionals and social care. Professionals are dealing with the lack of time and resources. There are social workers who have to coordinate themselves more with more than 40 family nurses. They go to the home of the care recipient, and they do the assessment needs of the carer and development of the carer support plan. Family nurses struggle to speak with others inside of the health unit, particularly psychologists and doctors. We also have a lack of institutional responses for people with high levels of dependence causing an overload on carers. With the new government, I'm already watching the film. In my 40 years of work, working groups are created, new people are appointed, and it becomes difficult to continue...So this is our story. We have magical. We did achieve a lot of things. But there is also tragic in terms of implementation, a lot of challenges, but step by step we are making our way.