

Scottish Universities Insight Institute project



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

Partner country profile: Canary Island - Spain

Context

(Source: *Cabrera Febles, I., et al. (2021). A Study on Family Caregivers in the Canary Islands. ACUFADE Inglés Completo.pdf - Google Drive*)

When we refer to caregivers in the Canary Islands, some of the most common names are María, Nieves, Pino, or Candelaria — mostly women. These “housewives” and “traditional” women were brought up with the explicit and implicit obligation to care for their relatives. This duty was enforced by customs, culture, traditions, and government structures, who know that guilt, the devastating feeling that appears when they “do not live up to the expectations” is their most potent ally. Women are taught that caregiving is their responsibility; that it is, fundamentally, “a woman’s thing.”

Some basic facts from the survey carried out in Canary Islands in 2021:

- 79% of family caregivers are women.
- 47% of caregivers reported dedicating more than a full workday (9 hours or more) to caregiving, with 39.1% spending more than 12 hours daily.
- Most dependent individuals assisted by family caregivers (75.5%) do not receive any kind of benefit or service related to the Dependency Act (SAAD).
- Only 21.5% of caregivers reported having the freedom to choose whether to perform caregiving tasks, and most of them feel obliged to undertake family care work (78.5%) due to moral, legal, and/or cultural reasons.

Carer policy:

Strictly from a legal perspective, it can be confirmed that there is indeed financial support intended for those who care for dependent people. In fact, in article 18 of the Act 39/2006 of 14 December for Promotion of Personal Autonomy and Assistance for Persons in a Situation of Dependency (SAAD, by its Spanish acronym), a specific subsidy is included, which determines that exceptionally and when the supported person is being cared for by their family environment and if the conditions established in the article 14.4 are met, an allowance will be given to cover the costs of family care.

Maximum amounts allocated for family carer for the Canary Islands in 2024 are:

- Grade 1 dependency: 180,00 EUR
- Grade 2 dependency: 319,08 EUR
- Grade 3 dependency: 504,00 EUR

Implementation:

The financial support from SAAD can be linked to different services, allocated to a professional carer or family caregiver. However, apart from insufficient finance, this provision conflicts with the lack of resources since its start! Although the conditions to receive this allowance are considered in the Resolution of 13 July 2012, the caregiver must have worked as a caregiver during the year before submission of the application. As a result, there is a delay of **up to 927 days** in processing this type of allowance.

The breach of legally required deadlines, the bureaucratic maze, and the permanent decrease of the financial endowment aimed at complying with the information laid down in the Dependency Act are the three main obstacles to the recognition and implementation of the rights of caregivers.

Facts from the survey: Among the current challenges concerning public administration and resources, the most relevant obstacles are waiting periods to access services and resources (87.6%), the lack of knowledge about available resources (84.6%), the number of hours of assistance granted (83.9%) and the bureaucratic application process (82.3%).

The law meant to protect the rights of individuals in situations of dependency as well as their care environment did not effectively achieve implementation, resulting in the deterioration of the assistance provided to dependent people and caregivers, who find themselves on waiting lists every year.

All these issues remain invisible and have not been tackled in political agendas. Furthermore, actions aimed at protecting the fundamental rights of caregivers have not been implemented either; that is why, despite the existence of a legal framework, care work remains today—as it has been considered historically—a duty assigned to women, alluding to cultural and moral claims rooted in our society.

What could help? What are some of the priorities in improving relationships between informal and formal carers?

- **Enhance administration services/structure:** The administration **must** reform its structure to a degree where the provision of rights is unaffected by internal shortcomings, ensuring efficient service delivery.
- **Consideration of territorial specifications:** Implementation of EU and national policies and strategies for caregiving **must** consider the unique characteristics of the Canary Islands (especially true for island territories). For example its reliance on tourism, which absorbs nearly all of its resources. Additionally, there is a growing deficit in creating professional spaces for caregiving, further intensified by both a growing elderly population and a decline in professional caregivers, placing added strain on family caregivers.
- **Change of development model:** where social care is the priority and is not “solved” simply by one law but is reflected in other aspects such as land planning (enough place for caregiving); educational system (to ensure professional care

and raise awareness on care); budgetary planning based and adapted regularly to respond actual needs of the territory.

- **Gender perspective:** currently the economic compensation for family care results mainly in women care. Traditions and stereotypes, together with low financial compensation, results in the fact that mostly women give up their work to care! Caregiving rent should force more men to care and should therefore consider economic elements (how much); social elements (who cares); educational elements (how to care); awareness elements (why care).

Canary Islands: territory that cares: Our aim is to ensure that Canary Islands can be acknowledged as a territory prioritizing the well-being of its residents: not only seniors, but also individuals of all ages requiring care. In this regard, particular attention should be directed towards immigration issues (both legal and illegal) as people come to the Canary Islands seeking better care than in their countries of origin. **Care should be recognized as a fundamental human right for each individual.**

Workshop one (October 2023) Researcher

I'm a psychologist at my NGO. Our main goal is to ensure that caring is a matter of choice and people who care can do this with dignity. I'm going to read you a real story.

Hola my name is Raquel. I'm 58 and for the last 10 years I took care of my mother-in-law, my dad and currently my mum with Alzheimers. Caring for them has not been a choice but a responsibility that I took on with all my love. I have been waiting more than 3 years to receive financial help from the government. The Independency Act offers a maximum of 800 euros a month to hire professional service or 500 for family care. I receive a pension but I have no other source of income and I had to give up my job for ten years. So I could never afford to hire a private service that costs around 2500 euros and the local government offers me a professional care giver for 3 hours a week when my mum's situation becomes very serious. But I needed more help. My friend told me about someone who agreed to help us for 500 euros. I know she deserves more and she will leave as soon as she finds a better job. All this affects my health. I can't sleep I'm suffering from back pain, arthritis and fibromyalgia. I recently started attending groups with other caregivers We give strength to each other and the psychologist told me to take care of myself but how can I do that if I don't have time to go to the hairdresser. Now I am reflecting at what cost did I care for my family. How much is the government saving on my sacrifice. And what will happen if I decided to stop caring for those who needed it the most. Thinking of my grandchildren I hope they can live in a society that values caring more and that does not save money off the shoulders of family carers.

This was Raquel's story but it could be many others or the majority of women in the Canary islands and also maybe other countries in Europe. We believe that family and professional carers are complementary but family carers should be perceived as an alternative and a choice. Currently it is an obligation. And the care system is depending on involuntary unpaid invisible work of family carers, mostly women, conditioned by traditional cultural legal economic aspects and of course gender stereotypes. And of

course stories like Raquel's are not an exception but a reality. I would like to finish with our caregivers demands. We don't seek for any more applause. We need and ask for resources. This begins with a law that recognises, regulates and protects caregivers.

Workshop two (December 2023) Unpaid carer

Hello, everyone. First of all, I want to say that I never thought dementia was such a terrible disease. My name is Anna. I don't have brothers or sisters in my family. We are only 3 people, my mother, who is 91, my aunt at 86, and myself. Therefore I have to take care of both of them.

My mother lives with me. Approximately 3 years ago I began to realize that she often forgot people's name, or didn't remember what she had eaten the day before, or what she had been doing during the day.

It was just the beginning. I could remember many beautiful, sad, or terrible situations this last years, but I will tell you this one, because it was one of the first times where I really was aware of my mother's illness. She underwent surgery on her left knee. I had to visit the hospital for 2 weeks. One day when I arrived to visit her. she started crying and screaming, saying that someone wanted to kill her. I tried to calm her down a bit, but I couldn't. I said to her, Mama, please keep calm.

She looked at me, as I was now a person. an enemy, and said that I was not her daughter, because she don't have children, and she continued, don't touch me, you are liar! I hate you! Oh, my God! It was so painful situation! I didn't know what to do. It was then that one of nurses came into the room and gave her one of her daughter's toys. A broad smile appears on my mother's face and then she turned to me, saying, This is the most beautiful baby we have ever seen, and it's just mine, and started singing a lullaby. Half an hour later I left, and at the point of leaving the room, my mother said. goodnight, honey. What time are you coming tomorrow?

From the light to the shadows. So is this disease, everything can be changed within the blink of an eye.

Workshop three (February 2024) Occupational therapist

One of the most significant moments of my work at Acufade is improving the quality of life of older adults with Alzheimers and their family caregivers through sensory experiences. We awaken the senses of older adults with Alzheimers, evoking positive feelings and experiences that reduce agitation and anxiety also through sensory activities. We also offer a space for relaxation and self-care, for family caregivers during sensory experiences. They experience decreased stress and emotional wellbeing through sensory activities.

This is the most beautiful and interesting part of my job offering support and positive experiences for older adults and their family caregivers.

My patient, due to Alzheimers. was experiencing moments of disorientation at home, causing episodes of agitation and high level of stress. She couldn't stop crying. Her family caregiver did not know how to relax her mother, causing her frustration in her daily life. After seeing the situation, I proposed that the patient and her family caregiver attend, a sensory stimulation session together to evoke positive and relaxing emotions after the session. The patient told me: "You have changed my daughter and my life. Thank you".