
ERWG Meeting 2024 – 12 November 2024

Gran Canaria, Spain

World Café Discussion – Group 1: The social contributions of informal carers

How Do Informal Carers Contribute to Their Communities Beyond Caregiving Tasks?

Their contributions span several areas, including social cohesion, economic support, and social innovation.

1. Contributions to Community Well-being

- **Promoting Empathy and Setting an Example**

Informal carers demonstrate empathy and resilience, setting a positive example for their immediate social circle. Their actions foster kindness and understanding, contributing to the development of a more compassionate society.

- **Economic Contributions**

By taking on caregiving roles, informal carers help reduce costs for public healthcare systems. Their unpaid work ensures that these systems function more efficiently, saving resources while supporting vulnerable individuals.

- **Providing Real Improvements in Care**

Informal carers often achieve significant improvements in the quality of care because they have the time and emotional investment to focus on the person's unique needs—something that overburdened professionals might struggle to offer.

- **Sharing Acquired Skills**

Through their experiences, carers develop valuable skills such as resilience, multitasking, and problem-solving. They often "give back" to the community by volunteering, providing advice, or mentoring others based on their knowledge.

2. Strengthening Social Cohesion and Relationships

- **Improved Relationships with Those Cared For**

The caregiving process often strengthens the bond between the carer and the person being cared for, deepening their connection and fostering mutual understanding.

- **Creating Chosen Families**

LGBT informal carers often build strong, supportive networks of relationships beyond their immediate biological families. These networks, often referred to as "chosen families," consist of individuals who share similar experiences, values, and mutual support. For LGBT carers, chosen families can be especially significant, as they provide a safe and affirming environment that may not always be available within traditional family structures. These connections foster a sense of belonging, solidarity, and understanding, which is particularly valuable when navigating the challenges of caregiving within the LGBT community.

- **Building Networks Through Activism**
Many carers become involved in activism, which helps them create new networks and establish connections between people and organisations.
- **Cross-fertilization of Ideas**
Informal carers often engage with different organisations, bringing innovative approaches and fostering collaboration across sectors.

3. Driving Social Innovation and Activism

- **From Self-help to Advocacy**
Informal carers often start with self-help or mutual-aid groups that evolve into advocacy organisations. These groups work at the local level to drive positive changes in policy and practice.
- **Breaking Stigma and Empowering Others**
By speaking out about their experiences, carers help reduce stigma surrounding caregiving and health conditions. They also encourage others to take on caregiving roles or advocate for their communities.
- **Facilitating Social Movements**
Informal carers often become enablers of social change. For example, movements like those led by mothers of children with disabilities have achieved legal recognition for carers, driving systemic change.
- **Innovative Solutions like Dementia Cafés**
Initiatives like dementia cafés (Ireland), often started by informal carers, provide social spaces for people with dementia and their families, combining care with community building.
- **Raising Awareness of Systemic Issues**
Informal carers highlight gaps in formal healthcare and social services, advocating for better quality care and raising awareness of critical issues.
- **Mobilising Neighbourhoods**
Carers can inspire community-based solutions such as "precaution circles" (Netherlands) where small groups of neighbours organise support systems, including coordinators to manage assistance effectively.
- **Empowering Women**
Caregiving roles are predominantly undertaken by women, and while these roles can be challenging, they also provide opportunities for empowerment. Through their experiences as informal carers, women often develop enhanced leadership and organisational skills which not only enable them to manage complex caregiving situations but also equip them to take on influential roles within their communities.

Raising awareness of the burden on women highlights inequalities but also celebrates their contributions, and supports efforts to promote gender equality and empowerment.