

WHAT DO INFORMAL CARERS NEED? TOWARDS A FAIR AND RIGHTS-BASED DEAL.

In Europe, 80% of all care is provided by informal carers – i.e. people providing usually unpaid care to someone with a chronic disease, disability or any other long-lasting health or care need, outside of a professional or formal framework. Although carers are the cornerstone of our long-term care systems, their contribution is seldom acknowledged and their needs rarely discussed. Yet, current societal trends (including notably the ageing of our societies, the increasing occurrence of comorbidity among dependent people, and the increasing mobility and changes in family structures) put informal carers under excessive pressure. The sustainability of their effort is at stake and without adequate support, these people are likely to reach a breaking point and become unable to provide quality care anymore. Some policies and practices have been developed to address this reality, mostly at local level, but they remain largely insufficient, extremely fragmented, geographically uneven and not always sustainable.

Since 2006, Eurocarers has been calling on decision makers to develop comprehensive responses to the needs expressed by informal carers, so as to ensure that their contribution is part of a fair deal. Informal carers' needs are both very basic and concrete, as they seek a better recognition of their role. This document aims to give an overview of these needs, which can only be met by ambitious policy developments and through societal changes involving all stakeholders.

Recognising informal carers' contribution – the need for a change of paradigm at various levels

At individual level, informal carers need recognition by and training of formal care services

providers (including in homecare) with regards to the central role they play. They should be acknowledged as equal partners in care and professionals should build on their experience and knowledge of the person they care for. More than this, carers should be involved in the decision-making process and be equipped with the information and tools required to deliver quality informal care. Too often though, informal carers are consulted to inform the diagnosis but are then left out of the loop, even though they are the ones ensuring compliance with treatment.

At a broader level, recognition means that informal carers should be involved in the design, delivery and evaluation of policies and programmes related to disability, social, health and long-term care, as well as in all initiatives concerning them. They should also be involved in the design of innovative technologies and practices aimed at facilitating caregiving. Lastly, carer' organisations that seek to empower them and voice their concerns and recommendations should be supported at local, regional, national and European levels. Besides, better awareness and recognition of the contribution and resource that carers represent for patients, society and the economy as a whole should entail a range of supporting policies and initiatives, as detailed below.

The provision of accessible, equitable and qualitative integrated services is essential to ensure that informal caregiving remains a choice

Differences in the provision of long-term care between EU members are more pronounced than in any other field of social protection. Ensuring accessible, equitable, qualitative long-term care for all is essential to provide

alternatives to informal care. Adequate home-care services are also crucial to ensure the possibility of combining professional and informal care for the benefit of a dependent person, and consequently to alleviate the burden of informal carers and contribute to improving the quality of care. Indeed, when homecare is available, informal care and professional care are not mutually exclusive but rather tend to reinforce each other in the interest of the dependent person.

People with multiple care needs usually receive long-term health and social care services from different providers in different care settings. This often happens without sufficient coordination, or any holistic approach, leading to various issues for service users and informal carers (gaps in service provision, inadequate support, lack of information, increased costs in the form of unnecessary hospital admissions or aggravated health problems, etc.)

Informal carers need social, health and long-term care services to be provided in an integrated way, centred on users.

Integration of services improves coherence, people-centeredness, empowerment and participation towards care and services. The European Commission has often underlined the importance of integrated approaches to the provision of social services. Integrated people-centred health services is also recommended by the World Health Organisation. Besides, informal carers – because they are at particular risk – must be granted specific attention as users of services of general interest. Indeed, while caring for a relative can bring a lot of personal satisfaction, the task is often taken up without any preliminary preparation, in the context of a crisis, by a relative who may already have other family or employment obligations. This can generate personal costs as being a carer is often associated with poverty, physical and mental health problems, isolation, employment-related issues and financial worries. Especially, health services should develop preventive measures targeted at carers, since they are at particular risk of developing health problems. The prevalence of mental health problems among informal carers is indeed 20% higher than among non-carers and research has also found various adverse effects on physical health.

In addition, carers need supporting services specifically tailored to help and empower them to manage their tasks and responsibilities. The following services have been identified as key enablers for quality informal caregiving:

- Information (What support tools and services are available? Which ICT-based solutions could help me? How can I access and use them? What are my rights and obligations as an informal carer? How can I get in contact with peers and exchange with people facing similar challenges?)
- Counselling and emotional support (How to cope with the emotional burden and contradictory feelings? How to manage my own mental and physical health? How to make choices?)
- Advice and guidance (How to organise the care of my relative? How to organise myself and juggle my responsibilities towards my family, my work, and the person I take care of? How to plan in advance?)
- Respite care (The possibility for the informal carer to be replaced so that he/ she can take some time off).
- Training (The possibility to develop skills related to daily care, health care as well as transversal skills – communication, ICT literacy, coordination and planning, etc. in order to help them care more easily).

One of the major obstacles when implementing such dedicated support services is the difficulty of reaching out to informal carers, and the lack of take up. This can be explained by the lack of accessibility to these services in rural areas, by the lack of free time available in the schedule of informal carers, making it extremely difficult for them to benefit from sustained support, as well as by the lack of relevance of existing services.

Also, research and experience have pointed out the lack of self-recognition by informal carers, which is underpinned by a lack of awareness and negative representation associated with informal care. Against this backdrop, we would like to suggest the following, based on the literature and expertise of informal carers.

Importantly, services geared towards informal carers need to be tailored to meet individual needs, depending on informal carers' personal situation (i.e. age, family situation, stage in their carer's journey, etc.) and on the specific difficulties faced by the dependent person they take care of.

In this respect, young carers deserve particular attention. Indeed their caring tasks often impact on various spheres of their life, including education and social participation. Young adult carers will have to juggle their caring responsibilities with their entry into the labour market, and the start of their own family.

Services geared towards informal carers will be picked up more effectively if they are part of comprehensive, integrated, participative and locally accessible packages of services, clearly signposted by all stakeholders at local level. Opportunities provided by new technologies for enhancing the accessibility of available support should be sized at their full extent.

Informal carers face major obstacles to access and remain in employment, as well as to fully realise their potential at work through upward mobility. This reality constitutes a violation of their human rights, as well as a waste of competencies for society as a whole. It also contributes to lock informal carers, and in particular women, in poverty and social exclusion.

The gender dimension is indeed particularly relevant here, since women provide approximately two third of care, and their role as caregivers can be seen as a factor of the gender pay and pension gaps, in addition to be factors of poverty and social exclusion.

An estimated 16% of the EU population of working age is combining full-time or part-time care with a job. The majority of working age carers are in employment: 50% of full-time carers and 70% of part-time carers work. Comprehensive policies aimed at helping at reconciling work and informal caregiving are needed. These should include:

- The possibility of taking a special leave for caring for a relative, likely to be used at short notice in case of crisis, accompanied with a protection against dismissal, and pension building rights;
- Secure and flexible working

arrangements, including a flexibility of working time matching the needs of the informal carer;

- The development of a carers' friendly environment in the enterprises, based on awareness raising, recognition and support to informal carers.

Options for flexible working time arrangements exist for carers in a few member states. But work/care reconciliation policies which, in combination with the provision of relevant services, would contribute to the social integration of informal carers as well as to increased employment and economic growth, still remain largely insufficient in Europe. In order to develop these much needed reconciliation measures, an adapted legislative framework, as well as actions by social partners acknowledging the positive impact of such measures to retain experienced workers in employment would be instrumental.

Unsurprisingly, given the obstacles they face to access employment, as well as the additional costs attached to caring for a relative (i.e. out-of-pocket expenditure for healthcare, costs of housing adaptation, etc.) informal carers are more likely to face poverty and social exclusion. Indeed, 42% of non-working carers are in the lowest income quartile (compared to 24% of non-carers), 59% of non-working carers have difficulty making ends meet (compared to 46% for non-carers). In 2011, citizens aged 55 or more identified financial remuneration for carers as the most useful things that governments could do to help informal caregivers, as part of a Eurobarometer survey.

Some member states grant allowances to informal carers, or to the dependent person, allowing him/her to pay his/her informal carer. Importantly enough, such allowances should be part of a comprehensive policy aimed at supporting the rights of informal carers, reconciling care and work, and allowing them to choose to take care of a relative in good conditions, in order to prevent low-skilled people from being trapped in their informal care role.

Innovative Ambient Assisted Living (AAL) solutions and Information and Communication Technologies (ICT) products and services that support carers have the potential to decrease the care burden, to contribute to a higher qua-

lity of life and increase the independence of the persons cared for. Informal carers should nevertheless be more systematically involved in the development of these solutions, and investment should ensure that all informal carers can access ICT-based innovation matching their needs.

The concrete needs expressed by informal carers are underpinned by the need to be considered positively and to have the skills they develop on the job recognised. A few Initiatives are being developed at local level which offer the possibility for informal carers to see their skills identified, strengthened and certified through ad-hoc training. Such recognition can bring informal carers with low educational attainment much needed self-confidence and empowerment, as well as a first step towards further training and inclusion on the labour market. Nevertheless, formal recognition of the skills acquired through caring remain extremely limited. Recognition, based on the validation of acquired experience, should be widespread.

Developing a carer-friendly ecosystem in our society as a whole seems to be a prerequisite on which progress in various areas can be developed and strengthened. To achieve this, all stakeholders across various sectors and policy areas need to come together.

Public authorities can play a decisive role to trigger such an approach, through the support to awareness-raising activities, a 'carer proofing' of all policies based on meaningful participation and access of informal carers to their rights. Public authorities at European, national, regional and local levels should take action.

Building a carer-friendly society also requires to fill the knowledge gap regarding carers in Europe. Research is indeed urgently needed at pan-European and national level to build a comprehensive, up-to-date picture of carers' situation. This knowledge base will be critical in informing policy in all areas affecting carers, especially in health, care, education, employment, social protection, transport and housing. It will also inform evidence-based practice concerning support services for carers and dependent persons.

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