

Eurocarers'
contribution to the
public consultation
on the **Social
Pillar's Action Plan**

November 2020

**Enhancing the Social
Rights of Informal Carers:
the way forward**

Contents

Introduction	3
1. APPROACH YOUNG CARERS AS A GROUP AT RISK.....	4
2. EXTEND CARERS' RIGHTS TO TRAINING AND LIFE-LONG LEARNING	7
3. A CARER'S LEAVE THAT MAKES A DIFFERENCE	10
4. ADEQUATE INCOME SUPPORT FOR CARERS	13
5. PENSIONS CREDITS FOR CARERS	16
6. AN AMBITIOUS EU INITIATIVE ON LONG-TERM CARE.....	17
7. AN EU STRATEGY TO SUPPORT AND EMPOWER INFORMAL CARERS	22
Conclusion	26
References	27

Acknowledgments

This publication has been prepared with the involvement of Eurocarers Policy Working Group, and builds on the contribution of the following members:

- Aidants Proche Belgique
- Anton Trstenjak Institute of Gerontology and Intergenerational Relations (Slovenia)
- Association Française des Aidants
- Anhörigas Riksförbund (Sweden)
- CAR.ER. (Association of informal carers of Emilia Romagna Region)
- Carers Finland
- Careum (Switzerland)
- Coalition of Carers in Scotland
- Family Carers Ireland
- Frank Goodwin (Ireland)
- Ivar Paimre (Estonia)
- VOCAL – Voice of Carers Across Lothian (UK)
- wir pflegen – Interessenvertretung und Selbsthilfe pflegender Angehöriger e.V. (Germany)

Contact: Claire Champeix cc@eurocarers.org

Introduction

Informal carers¹ play a central role in the provision of long-term care (LTC) in Europe. According to some estimates, as much as 80% of all care is indeed provided by families, friends and neighbours. Although their individual circumstances may markedly differ depending on the national social protection system in place, the local support they benefit from, as well as the type and intensity of care they provide, informal carers across Europe have common needs, concerns and demands.

The impact of the COVID-19 pandemic has dramatically exacerbated the challenges carers face, as many of them had to manage complex care situations in a context of restricted health and social care services, acute isolation and constant worry for the health of their relative as well as for their own. Informal carers only received very limited targeted support during the crisis, reflecting the lack of recognition and invisibility of informal carers in our societies. This is the reason why Eurocarers' members place great expectations in the Action Plan to implement the European Pillar of Social Rights. Ambitious and resolute action is indeed needed in a series of key areas where there is definitely room for improvement. Our contribution is therefore underpinned by a comprehensive approach, presented in detail in Eurocarers' proposed European Strategy on carers - ["10 steps towards carer-friendly societies across Europe"](#), and by our members' expertise and first-hand experience which allow to illustrate our asks with promising practices and policies in which they play an active role.

"Informal carer shouldn't feel abandoned"

At a time when Europe's overall increase in life expectancy and ageing demographics generate a growing incidence of age-related conditions and a growing demand for care in all age groups, carers' contribution to the sustainability of our care system and to the wellbeing of people in need of care is simply vital.

Some countries or regions have already begun to lay the foundations of carer-friendly societies. The EU must build on these breakthroughs to define common social standards for this vulnerable group whose role is so crucial, and to demonstrably improve the lives of 10 to 20% of the total European population. Addressing the diversity of carers' situations and needs, it is important to design custom-made measures targeted at carers while taking into account their perspective in a wide range of policy domains with a bearing on their daily life. The coronavirus crisis has done nothing but exacerbate the challenges facing carers, with a disproportionate impact on women who provide approximately two-thirds of informal care as daughters (in law), wives, partners and mothers of persons with additional needs. Besides its positive effect on the social situation of carers, enhancing the social rights of informal carers also holds great potential to efficiently combat gender inequalities. Moreover, implementing these recommendations, would also support the EU's efforts in delivering on the SDGs²,

¹ defined as persons who provide – usually – unpaid care to someone with a chronic illness disability or other long-lasting health or care need, outside a professional or formal framework.

² SDGs: In September 2015, at the United Nations General Assembly, countries signed up to the 2030 Agenda for Sustainable Development and its [17 Sustainable Development Goals \(SDGs\)](#). The EU has fully committed itself to its implementation.²

notably Goals n°1, 3, 4, 5, 8 and 10, and in ensuring that informal carers are able to enjoy their human rights, preserve their capacity to make sovereign and informed life choices, participate in society and be socially included.

1. APPROACH YOUNG CARERS AS A GROUP AT RISK

PRINCIPLES OF THE SOCIAL PILLAR IMPLEMENTED

1. Education, training and life-long learning

Everyone has the right to quality and inclusive education, training and life-long learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market.

11. Childcare and support to children

Children have the right to affordable early childhood education and care of good quality. Children have the right to protection from poverty. Children from disadvantaged backgrounds have the right to specific measures to enhance equal opportunities

OUR ASK: ADDRESS THE SITUATION OF YOUNG CARERS VIA THE NEW EU STRATEGY ON THE RIGHTS OF THE CHILD AND THE CHILD GUARANTEE

Both the EU Strategy on the Rights of the Child and the Child Guarantee, to be adopted in the Spring 2021, would miss an important target group were they to omit young carers¹.

Young carers are children and teenagers under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The impact of caring on young carers themselves is well documented. Having to reconcile the everyday challenges that life throws at them as children and teenagers with extraordinary caring responsibilities can be overwhelming. To make a difference, the EU should ensure that young carers are identified, supported, listened to and actively engaged in all decisions that concern them. In this objective Member States should agree on a common definition, measurable objectives, support to comparative research and exchange, and participatory processes.

WHY URGENT ACTION IS REQUIRED

While young carers are becoming more and more vocal about their needs, they still remain largely invisible in EU and national policy developments. Promising support measures nevertheless exist in some countries but remain totally insufficient to make a lasting difference. Recent comparative research highlights the potential to extend existing legislation, policy and service frameworks to include adolescent young carers, and the importance of recognising and raising awareness of young carers². **Whilst young carers can gain satisfaction from their caregiving and enhance their self-esteem, empathy and maturity, caring can also**

negatively impact on their development, compromise their education, mental health and social inclusion. Young carers have been identified as being at higher risk of becoming NEET (Not in Education, Employment or Training) due to a lack of self-confidence and necessary qualifications. In the UK, the likelihood of young adult carers being NEET for six months or more was twice that of their peers³. In Italy, the Youth Guarantee Report has highlighted that the responsibilities related to the care are the first reason of inactivity of the young NEET between 15 and 29 years. The trends at national level are confirmed at European level. According to Eurofound⁴, 15,4% of young people not in employment, education or training are in this situation because they are caring for children or incapacitated adults or have other family responsibilities.

Beside the social and educational aspects, **Human Rights considerations** also call for urgent action on this issue, so that young carers can enjoy the rights to which they are entitled, just like all children. These concerns are strengthened by **economic arguments**, as poor mental health, early school dropout and low employability levels are increasingly recognized as a cost not only for young carers themselves but for society as a whole.

Many of the **key stakeholders** whose work has a bearing on the daily life of young carers are often unaware of their existence and of the challenges they face. As a result, young carers remain invisible and their needs for support are not met. Stakeholders from different fields (e.g. policy makers, health and social care providers, school professionals, youth, care workers...) should be better aware of this reality and equipped to support young carers, as all of them have a role to play in the development of an environment in which young carers are able to pursue their goals and thrive, in line with the principles described in the UN Convention on the Rights of the Child (1989).

PROMISING POLICIES, PROJECTS AND PRACTICES:

Recent transnational European projects shed light on Young Carers

Two recent research projects have been finalised in 2020, that shed light on the specific needs of young carers and map out a range of promising supporting practices. These are:

“Me-We” (Psychosocial Support for Promoting Mental health and wellbeing among adolescent young carers in Europe): an ambitious research and innovation project, gathering 10 research and carers organisations, funded by the European Union under the Horizon 2020 Programme. The overall goal was to strengthen the resilience of Adolescent Young Carers in transition to adulthood (15-17 years old) in order to impact positively on their mental health and well-being and to mitigate the negative influence of psychosocial and environmental factors in their lives. See the outcomes of the project on [ME-WE website](#).

Innovative School Education Methodologies and Tools for Guaranteeing Social Inclusion of Young Carers (EDY-CARE) aimed to empower teachers and other school staff (e.g., school nurses, psychologists, social workers, management) in upper secondary education to recognise adolescent young carers (16-19 years old) in classes and maximize their learning opportunities, while ensuring their social inclusion. See the outcomes of the project on [EDY-CARE website](#).

“Motivation leads to success”: a comprehensive project addressing early school drop-out, including through support to young carers - Sweden

From 2017 to 2021, the Regional Association of Kalmar County ran a comprehensive project addressing the issue of school drop-out among teenagers, in cooperation with 5 municipalities and the regional association of upper schools, with the support of the European Social Fund. Various initiatives have been developed in order to reach out to and motivate students to complete upper secondary education. Practical work with the students who participated in the project has been carried out in seven sub-projects that affected 9 of the county's municipalities. Building on the outcomes of the two projects mentioned above, a sub-project has been carried out by the Swedish National Care Competence Centre (Nka) focusing on identifying and developing support for young carers. More information on the [Kalmar County webpage](#).

Switzerland: YC-Get-together service supports young carers' empowerment

In terms of empowerment, young carers often lack the space and opportunities to reflect on their situation on their own and together with other young people experiencing similar challenges and to stand up for their interests in a broader public in Switzerland. YC-Get-together is one of the first two services tailored to support young carers in Switzerland, developed as part of the "Caring youths and young adults between school, training and work" project aims to close this gap. . .

The Get-together programme offers young carers lasting support and thus makes an important contribution to ensuring that young carers are healthy and equipped with internal and external resources for dealing constructively with challenges. In terms of equal health opportunities, they make a successful transition into adult life.

The service was set up and evaluated during a pilot phase as low-threshold, professionally supervised exchange meetings for young carers aged between 15 and 25 years. The young carers, who now regularly attend these meetings, use the space created to establish contacts with young people in a similar situation, exchange experiences and concerns and give each other tips, whether in connection with their support role or on other issues such as training. The service accordingly contribute to the strengthening of the social network, life skills and self-efficacy expectations and thus to the mental health of young carers. The young carers are given the opportunity to determine the content and organisation of the meetings themselves. Among other things, the participants jointly think about ways to better support young carers in Switzerland. Community empowerment is thus strengthened. The meetings take place in person and always with the option of online participation. It has been shown that the young carers team's organisation and professional support of the meetings is highly appreciated and gladly taken up by the participants.

The service is funded by three foundations, is implemented at local/regional level and is planned to be available at national level in 2021. The get-togethers have been adopted by the Federal Office of Public Health as model of good practice for caring relatives. More information on the project is available on the dedicated [webpage](#).

The Netherlands: A buddy project for and by young carers

Ervaringsmaatjes is a project where a volunteer or student with experience as a young carer provides individual support to young carers and acts as a “buddy”. Given his/her personal experience, the buddy knows better than anyone what being a young carer is like and is there

for the child without any restriction, offering a listening ear, opportunities for socialization, as well as support on practical matters. (S)he also helps to gain insight into the personal wishes and needs of young carers.

This project has been rated as very effective in supporting the social life of (A)YC, in increasing social connectedness among (A)YCs, as well as in building resilience. More information on the project is available on the [dedicated website](#).

A national project for young carers in Finland

Building on relevant projects and research initiatives across Eurocarers network, the Project Jangsterit - Young Carers in Finland project was launched in 2016 by Carers Finland with the support of the Ministry of Social Affairs and Health. The aim of the project is to identify, reach out and provide support to adolescent and young adults with caring responsibilities, and develop awareness raising, training, research and advocacy activities.

On the first European Carers Day, on the 6th of Oct 2020, virtual seminar for professionals and volunteers were organised. More information can be found on the [project website](#).

2. EXTEND CARERS' RIGHTS TO TRAINING AND LIFE-LONG LEARNING

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED

1. Education, training and life-long learning

Everyone has the right to quality and inclusive education, training and life-long learning in order to maintain and acquire skills that enable them to participate fully in society and manage successfully transitions in the labour market.'

OUR ASK: Upcoming initiatives by the European Commission of relevance to carers (e.g. the European Education Area; the Digital Education Action Plan, the Skills Agenda and Skills Guarantee, the boosted ERASMUS+ budget, etc.) must address their needs.

WHY URGENT ACTION IS REQUIRED

Carers' skills must be recognised and valued

Many informal carers suffer from a lack of recognition for their unpaid work. Informal carers who are not included in the labour market often feel isolated and suffer from a feeling of self-depreciation. For those in employment, being an informal carer can be a source of stigma and is associated with reduced professional prospects, lower salaries and pension entitlements especially when they are compelled to opt for part-time work. This is particularly true for women who provide the lion's share of informal care and have to combine work and caring responsibilities, or exit the workforce to provide full time care. It also concerns young informal

carers who may face stigma at school, college or/university and difficulties to follow a standard educational curriculum, with a detrimental impact on further professional career.

Though, informal carers develop many competences through caring, ranging from medical skills to soft transversal skills (communication, time management, digital skills...). Training pathways that build on the experience of informal carers can help them become more aware of their knowledge and abilities, and obtain recognition of their skills, hence strengthening their self-confidence and motivation.

Adequate training is key to the sustainability and the quality of informal care

Ensuring that tailored-made training is accessible to all carers will contribute to maintaining their contribution, and sustaining the quality of the LTC they provide. Combined with effective support, it has a preventative aspect in avoiding or delaying hospital admission and long-term residential care, and preparing more efficient and earlier discharges.

Training, combined with support and respite care, is also key to strengthening resilience and preventing carer's burn-out, as well as reducing the risk of abuse and neglect of the person receiving informal care.

Generally, bringing together 'expert and peer learning' in carer training programmes has been recognised as providing a valuable mix of theoretical and practical learning and peer reflection in supportive environments. Existing community-based training not only focus on caring competence, but also on physical and emotional well-being, creating breaks from caring and developing life management skills. Furthermore, adequate training can equip experienced informal carers with tools enabling them to provide effective support to other carers, hence taking an active role in the community. In order to ensure quality of training, platforms for training methods development and sharing of good practices should be encouraged across Europe.

Tailor-made support, dedicated training opportunities combined with skills recognition contribute to combat carers' social exclusion.

Training associated with personalised support can help carers re build their confidence and take the necessary steps before entering professional training pathways likely to support their reintegration in the labour market⁵. Against the backdrop of care workforce shortage, validating the skills of informal carers, building on national and international skills validation models, can be a key step in a pathway to professional qualification in the care sector, contributing both to opening new employment opportunities and maintaining the sustainability of the LTC provision.

Digital literacy: informal carers at risk of exclusion⁶

The reduction or removal of face-to-face services resulting from the confinement measures has shed light on the potential offered by ICT-based solutions to support carers, through access to online support services and peer-support, thereby overcoming their isolation. However, such opportunities remain out of reach for a number of carers given their limited access to proper equipment, and a lack of digital skills. There is an urgent need to provide carers with the skills required to access such opportunities, as part of comprehensive approaches building on a combination of both face-to-face and online services. Indeed, while promising initiatives have been developed to provide carers with online support and

accompany the shift to ICT-based solutions, they remain scattered and should be scaled up and better integrated in the provision of social, health and LTC services.

PROMISING POLICIES, PROJECTS AND PRACTICES:

Erasmus+ project CARE4DEM Project: an innovative model of a Mutual Aid Group for informal carers of people with dementia facilitated online

The CARE4DEM project (2017-2020) designed and tested an intervention empowering experienced carers to facilitate on line peer-support groups for people providing care to a person with dementia. Volunteer carers were invited to identify and develop their skills through a blended training, before co-facilitating peer-support groups online with a health and long-term care professional. This training concerned a series of competences, including those related to caring for a person with dementia and competencies related to group facilitation and managing groups online. They were supported in using ICT devices and online features. The piloting of the intervention in Italy, Portugal and Romania, during a period of strict confinement, proved very satisfactory for participants and training facilitators. The project produced an entire set of tools accessible to all professionals and volunteers willing to replicate the initiative, including the necessary tools to conduct an evaluation. This project was supported by the Erasmus+ programme.

More information on the project on the [dedicated website](#).

Civil society organisations address the need for training, empowerment and peer support.

Organisations supporting informal carers in the field have been developing comprehensive training opportunities, responding to the most urgent needs. Such training help carers improving their knowledge and capacities to provide quality care, but also to maintain their own health and well-being, building on guidance and peer support in the community, as for example the training programme offered by VOCAL in Scotland or the Ovet-valmennus® training model developed by Carers Finland. A number of these opportunities are available partly or totally online, to facilitate the participation of those who have limited availabilities due to their caring responsibilities. Some of them give the possibility to participants to receive an attestation validating their competences upon completion of a training programme and final testing of the competence acquired. This is the case for example of the online training developed by 'La Compagnie des Aidants' (France) as part of an initiative supported by the European Regional Development Fund.

3. A CARER'S LEAVE THAT MAKES A DIFFERENCE

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED

9. Work-life balance

Parents and people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to use them in a balanced way.

OUR ASK: Member States should be incentivised to grant ALL informal carers access to leaves that meet their actual needs in terms of duration, eligibility, flexibility and financial compensation.

The promotion of work-life balance for working carers should be discussed with relevant stakeholders at national level, and supported by continued mutual learning, research and transnational exchange at EU level. Enterprises should also be encouraged to implement carer-friendly workplaces including meaningful possibilities to take time off.

WHY URGENT ACTION IS REQUIRED

While the adoption of the Work Life Balance Directive in 2019 and the establishment of a new right to a carer's leave of five days per year, represents a major breakthrough in the recognition of informal care, **the entitlement remains far from providing carers with the time off they need** to be able to retain work. Longer leaves, more inclusive eligibility criteria, more flexible work-life balance measures and financial compensation during the leave are need for all working carers irrespective of their employment status.

Currently, **the Directive does not foresee any compensation**, and leaves it up to Member states to specify the degree of flexibility of the leave and the eligibility criteria. Consequently, the transposition of the Directive at national/regional level often reveals simplistic and will not substantially improve the daily life of carers in those countries where embryonic provisions already exist. Hence, it fails to trigger public debate on the actual needs of carers, as in Finland where the Ministry of Economic Affairs and Employment recently established a steering group tasked with the evaluation of the changes needed in the Finnish legislation, which includes social partners but no carers' representatives.

Since the adoption of the Directive, and in some cases prior to that, **some governments have granted carers a more extensive right to leave**, in recognition of their needs and the added value of supporting their ability to balance work and care in order to prevent them from dropping out of the labour market, while supporting the quality of the care they provide. **Major companies, following the same path**, support those among their employees who also have caregiving responsibilities via extra days off, flexible working time or measures to minimise financial disadvantages. They also facilitate, by positive action, an understanding of carers work-life balance challenges among the general body of staff and management.

As it stands today, there is the risk of seeing imbalances between and within member states widen, with carers being better recognised and supported in some places than in others. On the contrary, **upward convergence should be sought, through resolute action at EU level.** This is especially the case at a time when, in a context of economic crisis and booming unemployment, workers' rights might be at risk.

PROMISING POLICIES, PROJECTS AND PRACTICES

Belgium: official recognition of informal carers

In Belgium, a law adopted in 2014, and adapted in 2019, grants **official recognition** to informal carers, should they belong or not to family of the person to whom they provide care. This general recognition gives the possibility to all informal carers to identify themselves to their health insurance, hence contributing to awareness-raising, prevention and an overview of the extent of informal care in the country.

In addition, as of 1st September 2020, under certain criteria regarding the intensity and the duration of the care provided, informal carers are granted a right to a leave of one month, which can be taken 6 times over the duration of the career, and which is compensated up to 1400 euros for the month if taken full time. Informal carers can either take the leave full time during one month, or reduce their working time by 50 % during 2 months, or by 20 % over 5 months⁷.

Apart from this specific leave, Belgian labour law has provided for several employment-family reconciliation provisions, for various employment status in the public or private sector, for the self-employed and the unemployed, addressing various situations from parenthood to palliative care.

All of these different forms of leave can be taken separately or combined and help informal carers coping for several years. The periods of leave are also counted as contributions to other social security benefits such as pensions, health insurance or protection against dismissal. Finally, they are accompanied by allowances which vary according to different criteria⁸.

France: introduction of a financial compensation for the carer leave

Since October 2020, the pre-existing carer leave is now financially compensated, up to 52 euros per working day for a person living alone, 43 euros for a person living in a couple, for a maximum of 66 days.

This leave is to be asked to the employer, and can be taken for up to three months several times in a career, with ceiling of 12 months. It is applicable to care provided within the family (to parents, children, spouses...), to relatives with a certain level of dependency, and concerns employees from the public and private sectors, self-employed as well as the unemployed. This compensation has been welcome as a concrete form of recognition of the role of informal caregivers in society.

In Ireland, a generous arrangement, though lacking flexibility

In Ireland the Carer's Leave Act 2001 allows employees who have been with their employers for at least 12 months to leave work temporarily to provide full-time care and attention for someone who needs it. A carer can take Carer's Leave for a minimum of 13 weeks and up to a maximum of 104 weeks (2 years). While periods of Carers Leave are unpaid, most employees will be entitled to receive a weekly **Carers Benefit payment of €220**. The payment is not means tested but rather is based on the carer's social insurance record. While on Carers Leave the carer is allowed to work for up to 18.5 hrs per week, however their employer is not obliged to facilitate this reduction in working hours⁹.

While Ireland's Carer's Leave Act 2001 offers working carers amongst the most generous leave arrangements of any country, one of its main drawbacks lies in the fact that it is often an all or nothing intervention, meaning working carers must leave work altogether for up to two years, unless their employer agrees to allow them to reduce their hours of work to 18.5 hours –which they are not legally obliged to do This in effect forces working carers out of employment when in fact in many cases all that is required is more flexible working arrangements. The process to require Carers Leave is also a quite formal and long as it can take anywhere from 6 to 12 weeks The Directive on Work Life Balance provides the opportunity to address these shortcomings by offering working carers the right to a minimum of 5 days carers' leave each year and the right to request flexible working arrangements as critical precursors to Carer's Leave.

In Germany, an independent advisory board on work-care reconciliation sets ambitious standards

The German Federal government set up an Independent Commission for the Reconciliation of Employment and Care in 2015. The Commission reported in June 2019 with far-reaching recommendations in many areas, including the recognition of carers' role, their right to leave from work, their health, financial support, information and advice, availability of formal LTC services¹⁰. These recommendations are now considered by government, employers and other agencies and are expected to feature in Germany's Bundestagswahl election programmes in 2021.

4. ADEQUATE INCOME SUPPORT FOR CARERS

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED

14. Minimum income

Everyone lacking sufficient resources has the right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services. For those who can work, minimum income benefits should be combined with incentives to (re)integrate into the labour market.

OUR ASK: THE EU SHOULD ENSURE THAT INFORMAL CARERS ARE NOT PUSHED INTO POVERTY AS A RESULT OF THEIR CAREGIVING, BUT RATHER OFFERED A FAIR DEAL.

Joining other civil society organisations in their call for a strong EU initiative to combat poverty and social exclusion, we demand that any initiative in this area addresses the situation of informal carers adequately, recognising their contribution and **ensuring they can access adequate income, empowering services and support in relation to employment**. Against the backdrop of the current economic crisis, it is urgent that all member states **protect informal carers effectively from poverty**, and take the necessary steps to **build relevant packages of income allowing people to make free choices** between different care arrangements, without being financially penalised.

The EU should further support comparative analysis of national/regional schemes gradually put in place to support carers financially, assessing their advantages and shortcomings, hence supporting member state in the design of adequate support schemes fitting in their own social protection system. The EU should guide member states toward **the agreement on a fair deal for informal carers**, through a dialogue with stakeholders including carers.

WHY URGENT ACTION IS REQUIRED

Over the past 30 years, the EU has built a policy framework to tackle poverty and social exclusion and emphasised the importance of adequate minimum income support. Key milestones include, amongst others, the 1992 Council Recommendation on common criteria concerning sufficient resources and social assistance in social protection systems and the 2008 European Commission Recommendation on active inclusion. Still, the outcome falls short of the EU target to lift 20 million citizens from poverty by 2020, and poverty and inequality are rising again in the context of the current pandemic. There is a growing consensus on the need to buffer the devastating impact of the economic crisis on the most vulnerable via efficient social protection, as illustrated by the conclusions on “strengthening minimum income protection”¹¹, approved by the Council last September.

Evidence shows that informal caring is **a determinant of poverty and social exclusion**¹². Indeed, providing care, especially intensive care, to a relative often entails a substantial economic cost: informal carers may be forced to cut down their working time or leave paid

employment altogether hence reducing their income, while contributing to the costs associated with the chronic condition of the person for whom they care (out-of-pocket expenditure for essential medical costs, additional material, treatments not covered by health insurance... etc.). Moreover, **accessing adequate housing enabling relatives to provide safe, efficient and adequate care at home represent an often-unattainable challenge**, as this might require housing adaptation, extension or event rehousing to a more suitable accommodation. The lack of suitable housing adaptation brings the risk to undermine carers' health and the quality of care.

Care responsibilities are **often a driver of 'inactivity'**, when conciliation reveals impossible. The conditionality criteria accompanying social benefits in some cases may not take caring responsibilities into account, leading to situation where non-working carers are disproportionately affected by poverty. In 2016, 45% of non-working carers were in the lowest income quartile (compared to 25% of non-carers), 54% of non-working carers had difficulty making ends meet (compared to 38% of non-carers)¹³. On that matter, in its above-mentioned conclusions on "strengthening minimum income protection", the Council has called for *"adequate consideration to be given to household composition and specific individual needs, for instance disability, childcare or long-term care"*. How to best support financially informal carers is now being more and more discussed at national level, as for example in France.¹⁴

Informal carers, whether they care for an older person in need, a person with a disability or a chronic disease, all face a **disproportionate risk of social exclusion** in its wider sense given the difficulty in participating fully in society and benefitting from equal opportunities due to their proneness to isolation, stress, and mental health problems, in particular when not employed¹⁵. However, carers provide an essential contribution to the sustainability of our LTC systems, while meeting the widespread preference of receiving care at home, at a time when the shortcomings of institutionalised care are becoming more and more obvious in the context of the pandemic's public health risks.

For all the above reasons, the risk of social exclusion of carers should be addressed via a comprehensive '**active inclusion**' approach, combining adequate income, access to services and person-centred support aimed to facilitate work their integration into sustainable, quality employment for those who can and for those who cannot work their social participation^{16 17}. Such should aim at preventing informal carers, in particular women, from being trapped in their caregiving responsibilities, but rather empower them to reconsider their role as necessary.

PROMISING POLICIES, PROJECTS AND PRACTICES

A **general overview of existing measures** shows that a number of European countries have introduced financial compensation for carers in one form or another, as part of a trend to formalise informal care as a component of the overall LTC provision¹⁸. However, such compensations are, in most cases, far from sufficient to prevent poverty. Often, they do not correspond to rights but rather depend on local authorities' priorities and financial means. For example, in Estonia, in 2019, the average annual carer's benefit per beneficiary was €510 (ranging from 16 to 212 euros per month), and the average payment per month for a carer providing care for an adult was €45 (€70 in the case of care provided to a child). These

disparities indicate that there are no minimum standards in provision of the benefit, which is allocated at the discretion of local government on an ad hoc basis¹⁹.

Ireland: recognition of the right to Carers Allowance since 2001

In Ireland a Carers Allowance is available to fulltime family carers who care in excess of 35 hours per week and where the person receiving care has been medically certified as in need of fulltime care. The Carers Allowance is also regarded as a 'gateway' payment, meaning receipt of the payment also secures automatic access to other financial supports including a Carer GP Visit Card (giving free access to GP care); an annual Carer Support Grant of €1,850 paid to the carer in respect of each person they care for; an entitlement to free travel on all public transport and; a Household Benefits Package (where the carer lives with the person receiving care) which gives discounts on monthly utility bills and exempts the carer from having to pay for a TV Licence.

The Carers Allowance is means tested, meaning families with a total gross household income of less than €37,500 will qualify for the maximum weekly Carers Allowance rate of €219, slightly above the basic social welfare rate set at €203 per week. Carers with a gross household income of between €37,500 and €61,000 will qualify for a reduced rate. As a result, some carers live on a combination of income from part-time work and Carers Allowance at a reduced rate which can amount to less than the basic welfare.

Carers' organisations have lobbied to have Carers Allowance benchmarked against average industrial earnings and are calling for carers to be recognised as a unique group within the social welfare system given their enormous contribution to the economy.

Scotland: Carers' allowance and introduction of a young carer payment

Carers' allowance in the UK is a dedicated payment to informal carers. It is an 'employment replacement benefit', for people caring for more than 35 hours a week and earning less than £128 a week net.

The good practice example is Scotland, where the government has raised carers' allowance by an additional £460 per year to bring it in line with 'job seekers' allowance'. Besides, a young carers payment was introduced in October 2019 to enable young carers to get respite and access life opportunities which are the norm for many other young people, as they make the transition into adulthood. It is a yearly payment of £305.10 granted to carers aged 16, 17- or 18-years old caring for an average of 16 hours a week for a person in receipt of certain disability benefits. Hours of care for up to three people can be added together to reach the 16 hours threshold.

5. PENSIONS CREDITS FOR CARERS

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED:

15. Old age income and pensions

Workers and the self-employed in retirement have the right to a pension commensurate to their contributions and ensuring an adequate income. Women and men shall have equal opportunities to acquire pension rights. ***Everyone in old age has the right to resources that ensure living in dignity.***

OUR ASK: THE TIME DEVOTED TO INFORMAL CARE, BE IT IN THE CONTEXT OF PART-TIME EMPLOYMENT, A CARE LEAVE OR A CAREER BREAK, SHOULD QUALIFY FOR PENSION CREDITS.

The action plan to implement the Social Pillar should clearly include this ambition and foresee how member states will be supported to achieve it.

WHY URGENT ACTION IS REQUIRED

Income replacement during caregiving and social security contributions, in particular pension contributions, are interrelated features which are key to protect carers against poverty over the life course. The lack of access to adequate pensions for those who have devoted important periods of their life to care is an important gap in social protection, with considerable repercussions in terms of **female poverty in old age**.

Informal care is now clearly identified as a determinant of the gender pension gap. Women indeed tend to provide much more unpaid work within the household than men, including LTC for relatives, resulting in greater absence from the labour market, which in turn, leads to lower pay and lower pension rights. The risk of poverty increases with age, especially in retirement, when women receive retirement benefits that are - on average - 40% lower than those of men.

Pension schemes continue to reflect the 'male breadwinner model'. Women are seen as dependent family members who have to rely on derived pension rights. Many women (especially older women who have not had any formal employment during their lifetime) can only rely on survivor benefits, calculated in relation to the pension of the late spouse. The adequacy of survivor benefits is problematic in many countries and in some cases, it places women at risk of poverty. **Adequately crediting periods of care in the pension system**, in combination with work-life balance policies, LTC services, and combating gender stereotypes, can help to ensure more adequate pensions for women.²⁰

There is now **a consensus on the need to give informal carers adequate pension rights**. Not only do organisations representing older people press for such an approach to be implemented²¹, but it is also proposed by the High-level Group of Experts on Pensions at Council level, who recommended "appropriate compensation for those whose care responsibilities have caused career interruptions"²²²³, as well as in the recently published Gender Equality Strategy 2020-2025²⁴. In spite of this, the vast majority of informal carers are still denied access to what should be considered as a key component of their right to social protection.

PROMISING POLICIES, PROJECTS AND PRACTICES

A lack of comparative data

No comprehensive comparison on the coverage and adequacy of the pension rights attached to care across EU is available. Eurocarers has identified a series of countries where some provisions exist at least in some situations (AT, BE, DE, DK, FR, IE, UK, LU, MT...). In Austria for example, there has been a growing recognition of the role of informal carers, who are entitled to a number of benefits such as free health insurance and pension contributions paid by the federal Government. In France, recent measures strengthen carers' rights to pension under certain conditions²⁵. However, in most cases, these provisions remain insufficient.

Ireland: new measures taken to tackle the care pension gap

Ireland's new government committed to "*develop a pension solution for family carers, the majority of whom are women, particularly those of incapacitated children, in recognition of the enormous value of the work carried out by them*"²⁶. There has been a growing recognition for a number of years that family carers are amongst those most disadvantaged by the current State Pension system, and even before this commitment was made in 2020 efforts had been ongoing to address this anomaly. For example, under a new approach to the calculation a person's entitlement to the State Pension Contributory due to come into effect in 2021, a carer who worked and paid contributions for only 10 years and then left the workforce for 20 years to provide care, will be given a State Pension equivalent to that of a person who worked in paid employment and made contributions for 30 years. While this new system is due to come into universal effect in 2021, the State has been using trailing new method of calculation since 2017 with family carers being the main beneficiary.

6. AN AMBITIOUS EU INITIATIVE ON LONG-TERM CARE

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED

18. Long-term care

Everyone has the right to affordable long-term care services of good **quality, in particular home-care and community-based services**.

OUR ASK: An ambitious legislative initiative on LTC should be launched at EU level whereby member states commit to upward convergence in the provision of accessible, affordable qualitative person-centred services, with a focus on home and community care.

This initiative should address issues arising in relation to both formal AND informal LTC provision, including the provision of comprehensive support targeted at informal carers. The initiative should encourage member states to deliver progress towards compulsory quantified target indicators on the accessibility and quality services. Such indicators should be commonly agreed through a participatory approach, and member states effort to deliver on the 18th principle should be supported through the combination of mutual learning, benchmarking, comparative research and funding. This initiative should foresee a governance process along

which all stakeholders at EU, national, regional and local level (including informal carers) are involved. It should encourage comprehensive strategies for LTC to be developed overcoming 'silos' approaches and building on cooperation and innovation.

WHY URGENT ACTION IS REQUIRED

Europe's overall increase in life expectancy and ageing demographic is generating a growing incidence of age-related conditions, **a growing demand for care in all age groups and a serious sustainability challenge for care systems**. This is exacerbated by an ageing EU health and social care workforce, problems with staff retention due to demanding working conditions and relatively low pay in some occupations, as well as the need for new skills and competences as a result of new care patterns and the rise in new technologies. As the EU has mentioned in its Country Specific Recommendations, formal LTC services have been widely seen as underdeveloped in many Member States²⁷.

An **increasing pressure is being put pressure on informal carers** who - in most European countries – already provide a large part of LTC for dependent people: in Europe, 80% of LTC is provided by informal carers²⁸. LTC is provided mostly by women, which is having a sizable impact in terms their participation in the labour market and the gender pay and pensions gaps. Moreover, carers are providing growing complexity of care regime, medications, procedures e.g. dialyses. The involvement of older people in informal care also brings a set of challenges. Today, more than 16% of people aged 65+ are providing informal care²⁹, many of them having their own health problems, and facing negative outcomes as regards their well-being and caring-life balance. These challenges are consistent across EU member states. The pandemic has only shed light on the role of informal carers, who have been providing care to and protecting the most vulnerable when number of services were suspended, on top of other family and/work responsibilities.

In recent year, **the added-value of EU cooperation with regards to LTC has become more and more obvious**. An EU commitment has emerged, with the ratification by the EU of the UN Convention on the Rights of Persons with Disabilities (2011), the adoption of Guiding principles on active ageing and solidarity between generations by the European Council (2012), and the adoption of the 18th Social Principle. Having adopted a voluntary framework for social services (2010), the Social Protection Committee is working on comparable indicators in the matter. Access to LTC services appears also as an issue of convergence between and within member states, with some rural areas combining demographic ageing and lack of LTC services³⁰.

Now is the time for the EU **to articulate clear common objectives assorted with efficient tools** and mechanisms of coordination between various stakeholders involved and policy areas concerned. Informal carers, together with people receiving care, must be **involved in the design, implementation of this ambitions EU initiative that we are calling for**. At its heart must be the principle of choice -the choice of each person to determine how much care they are able and willing to provide, the principle of self-directed support, the right of each person to determine the care they receive-, and the recognition of informal as equal partners in care. Indeed, as underlined by the European Foundation for the Improvement of Living and Working conditions "*understanding today's needs requires acknowledgement that care needs*

and care provision affect not only the persons in need of care, but also their households and their informal carers. This reinforces the view that formal and informal care should be seen as complementary services – equal partners - rather than alternatives to each other. With the emphasis on community and home care in the European Pillar of Social Rights, this is particularly important.”³¹

In this respect; much progress remains to be done. Typically, breaks from caring (**respite care**), providing informal carers a much-needed break as well as an opportunity to articulate more closely informal and formal care for the benefit of the person receiving care, are far from being accessible to all, while at the same time being increasingly recognised as a crucial service.

More globally, an EU initiative on LTC should aim to develop **integrated health and social people-centred care**³², so that users receive a continuum of preventive, curative, rehabilitative, and support interventions throughout the life course which are suited to their needs over time and are seamlessly available across different levels and areas of health and social systems. In cases when relatives and/ or friends are willing and able to deliver care, such an integrated care system should provide the support they need. **Care needs should be regularly assessed** as demands on carers grow with the passage of age and changes in their own health and that of the person receiving carer.

The inclusion of informal carers and organisations that represent them in Integrated Care Partnerships must become a central principle to release the full potential for mutual beneficial synergies across services, better allocates resources and avoid overlaps and the negative effects and costs of service disruption on health status.

PROMISING POLICIES, PROJECTS AND PRACTICES

England and Wales: Social prescribing to overcome silos between professionals and services, empower people in need of care, support community-based services and build person-centred care solutions.

Social prescribing is a concept that has arisen in practice and implemented widely in the United Kingdom. It has been evaluated by various organisations. A highly successful network on Social Prescribing Network co-chaired by Dr Marie Polley from early 2016 expanded to over 3000 individuals representing a range of stakeholders and sectors including health care, public health, social care, allied health professionals, Voluntary, Community and Social Enterprise Sector (VCSE), academia, patients, citizens, and practitioners.

Social prescribing is being developed as a mean of enabling General Practitioners and other frontline healthcare professionals to refer patients to a link worker - to provide them with a face to face conversation during which they can learn about the possibilities and design their own personalised solutions, i.e. ‘co-produce’ their ‘social prescription’- so that people with social, emotional or practical needs are empowered to find solutions which will improve their health and wellbeing, often using services provided by the voluntary, community and social enterprise sector³³. The governments National Health Service Long Term Plan (Jan 2019) includes a plan for Social Prescribing.

More information can be found on the website of the Westminster International Centre for Social Prescribing: https://www.westminster.ac.uk/research/groups-and-centres/westminster-international-centre-for-social-prescribing#about_us

Scotland: In Scotland social prescribing is applied to mental health services (<http://www.healthscotland.scot/publications/social-prescribing-resources>) and a Social Prescribing Network is developing this practice further (<https://www.socialprescribingnetwork.com>)

UK: Dementia Friendly communities

A dementia-friendly community is a city, town or village where people with dementia are understood, respected and supported. Dementia-friendly communities are vital in helping people live well with dementia and remain a part of their community. Too many people affected by dementia feel society fails to understand the condition they live with, its impact or how to interact with them. That's why people with dementia sometimes feel they need to withdraw from their community as the condition progresses.

The Alzheimer Society has developed a dementia-friendly communities programme encouraging everyone to share responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community. Communities are invited to meet essential criteria in various areas, ranging from transport and retail to GP practices,

A recognition process enables communities to be publicly recognised for their work towards becoming dementia-friendly. The process asks communities to commit to delivering change and is structured around 2 key documents the BSI Code of Practise for dementia friendly communities and, the Alzheimer foundation criteria for dementia-friendly communities. There are more than 200 dementia-friendly communities in England today.

More information on dementia friendly communities can be found on the Alzheimer society website: <https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities>

Estonia: a package of measures in preparation, aimed to respond to the growing needs for LTC through a combination of formal and informal care provision.

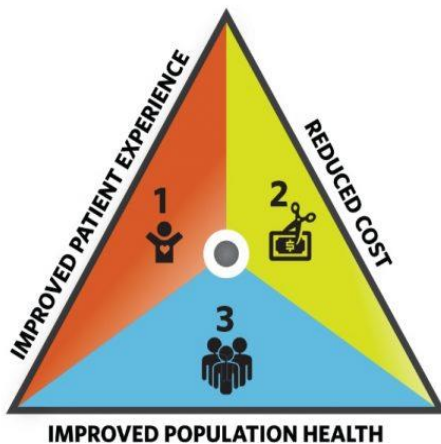
In 2015, the Estonian government, responding to concerns raised during the Parliamentary elections' campaign and intense advocacy work; initiated a process aimed to address the challenges in the field of LTC, including the situation of informal carers. A Task Force was set up, which released in 2017 a report³⁴, calling for urgent action in the fields of formal and informal LTC provision. A report was also commissioned to the World Bank with the support of the European Social Fund, sketching out the possible policy options, stressing that *“the urgent policy priorities are to: address inequalities in services provision by redistribution of funding to those local governments with weaker funding capacity; and increase financial and social support to informal carers [who] will continue to be the backbone of the LTC system for the immediate future.”*³⁵

LTC is definitively on the agenda of the current government, who set up a Working Group in February 2020, currently finalising its recommendations. The latter are expected to include a legal definition of informal carers, support measures (adequate services, training, care coordination) and common rules concerning a more generous carer's allowance. Indeed, while priority should be given to the development of formal care provision on the long-term through renewed partnerships between the state and local governments, informal care is also recognised as one of the pillars of LTC provision.

Sweden: a training for professionals on how to support carers adequately

Filling a gap in formal education, a specialisation training course has been created for all professionals likely to meet informal carers throughout their activities, and potentially support them and arrange care with them. This training provides a multidimensional approach to the challenges linked to informal care, and gives a series of tools to cooperate with informal carers as a professional in an efficient way. It is delivered in cooperation with the National Association of Carers (Anhörigas Riksförbund). More information on the training [here](#). Along the same lines, training developed by carers organisations often offer tools to both carers and professional to improve mutual understanding, communication and cooperation (for example the French Association Française des Aidants in their [training programme](#)).

Belgium: Pilot projects implementing integrated care for people with a chronic disease.



12 multidisciplinary integrated care pilot projects started on January 2018 across Belgium. The well-being of patients with chronic illnesses can improve, if a more integrated approach to care is implemented. The patient must be at the centre, empowered so that he can take responsibility for his care, while being supported by a multidisciplinary network. This network includes, among others, the general practitioner, specialists, pharmacist and nurses, but also social workers, and informal carers. The members of this network work together and with the patient. Each partner can share their own expertise in the most

efficient way. Current pilot projects test methods for organizing integrated care for chronic patients, in a specific region, on the basis of a “Triple Aim” approach (below), while paying particular attention to the quality of life of health care providers and the principle of equity. More information on the programme website: <https://www.integreo.be/fr>.

Professional support and coordination of predominant informal care – introduction of local informal care coordinators into the public system: Anton Trstenjak Institute proposal for the Slovenian bill on long-term care 2020

Local coordinator of informal care in public system ensures that local needs for training, empowerment and peer support are met. Beside leading the local network of volunteer carers, this person is in charge of coordination with formal care ensuring better integration of care and more efficient financial and formal support of informal carers enabling them to better carry on their caring responsibilities. In Slovenia this role is currently partly covered by network organizers working for municipalities that are part of Slovenian network of Age-Friendly Cities and Communities coordinated by Anton Trstenjak Institute. But it was proposed by the Institute and consortium of Slovenian municipalities that a role of local coordinator of informal care should be adopted nationally through Slovenian long-term care act.

7. AN EU STRATEGY TO SUPPORT AND EMPOWER INFORMAL CARERS

PRINCIPLE OF THE SOCIAL PILLAR IMPLEMENTED

3. Equal opportunities

Regardless of gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation, everyone has the right to equal treatment and opportunities regarding employment, social protection, education, and access to goods and services available to the public. Equal opportunities of under-represented groups shall be fostered.

OUR ASK: the adoption of a dedicated EU strategy for carers should be the starting point of an ambitious, consistent and comprehensive effort to address the needs of carers across the EU.

Such a strategy should ensure that the willingness to support and empower carers is articulated around a common definition of informal care, a set of measurable outcomes, the achievement of which will be supported by the adoption of relevant indicators, research, policy exchange and monitoring as well as adequate funding. “Eurocarers’ Strategy to support and empower carers”, which presents a coordinated set of 10 steps to be taken in order to develop carer-friendly societies can be a great source of inspiration for this initiative. Besides, awareness activities could be developed around the newly-launched [European Day of informal carers](#).

This European Strategy would ensure that supporting and empowering informal carers remains a lasting priority in the European Agenda in the coming years, that action taken in the many policy areas with a bearing on carers (employment, health, digitalisation, gender equality, social inclusion, service provision, etc.) , are all duly coordinated and mechanisms that ensure the participation of informal carers in the design and implementation of policies affecting them are in place

WHY URGENT ACTION IS REQUIRED

It is clear that carers are an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems. They will become even more important in view of the changing health and care needs, due to demographic ageing and the increasing prevalence of frailty and chronic conditions. However, whereas caring responsibilities, often taken on by necessity in a context of insufficient LTC services, have a huge impact on one’s health status and socio-economic situation, carers do not get the recognition and the support they need. On the contrary, they should be considered as a group at risk of vulnerability, and deliberate action should be taken to ensure they have equal opportunities. Among carers, the concerns expressed by certain groups such as young carers and older carers should receive particular attention.

The value of informal care in Europe is not only a matter of finances. Informal care and solidarity also have **an intrinsic value from a moral standpoint**, i.e. standing and caring for vulnerable groups (e.g. people who are chronically ill, persons with disabilities and frail older people) not because of any personal interest, but because they need this support. Caring, and its impact on both those who carry out the role and those who receive care, engages civil, political as well as social rights. The provision of the latter in particular, requires positive actions by the State and investment of public resources³⁶.

Over the last few years, much has been achieved in taking forward the carers' agenda at international, EU and – to some extent – national and regional level. However, the success of initiatives aiming to address the needs and preference of carers largely depends on the interplay between a broad set of policies in the social, health and employment fields.

Yet, policy developments of relevance for carers have often been implemented in a fragmented and uneven manner and have therefore not always resulted in real improvements in carer support, leading - sometimes - to a breakdown in trust between carers and decision-makers and service planners.

Much more needs to be done to achieve practical support on an all-inclusive and multidimensional basis, to ensure synergy and consistency between existing EU, national and regional policy initiatives, to trigger new ones in support of carers, and to ensure carer's participation in the design and the implementation of policy that concern them. The need for a comprehensive approach has been recognised and implemented in some countries and regions: the European Strategy might build on these initiative's and help evaluate their transferability.

PROMISING POLICIES, PROJECTS AND PRACTICES

Italy: a comprehensive approach in the Emilia-Romagna Region

The regional law of the Emilia-Romagna Region³⁷ introduced in 2014 defines for the first time in Italy an informal carer, as “a person who voluntarily and free of any charge takes care of a person with care needs who allows him/her to do so”. Informal care may involve assistance with housekeeping, mobility, accessing services and social relations.

This important law:

- Recognizes the role of the informal carer and its value for the society as a component of the local network of services to the person:
 - Defines carer's subjective rights (information, training, psychological support, planned and emergency relief) and representation rights;
 - Foresees carers' active involvement in the definition of individualised care plans;
 - Foresees financial support through care allowance and recognition of skills acquired through caring,
 - Provides for support for conciliation (agreements with employers' associations),
 - Establishes the regional Caregiver Day...

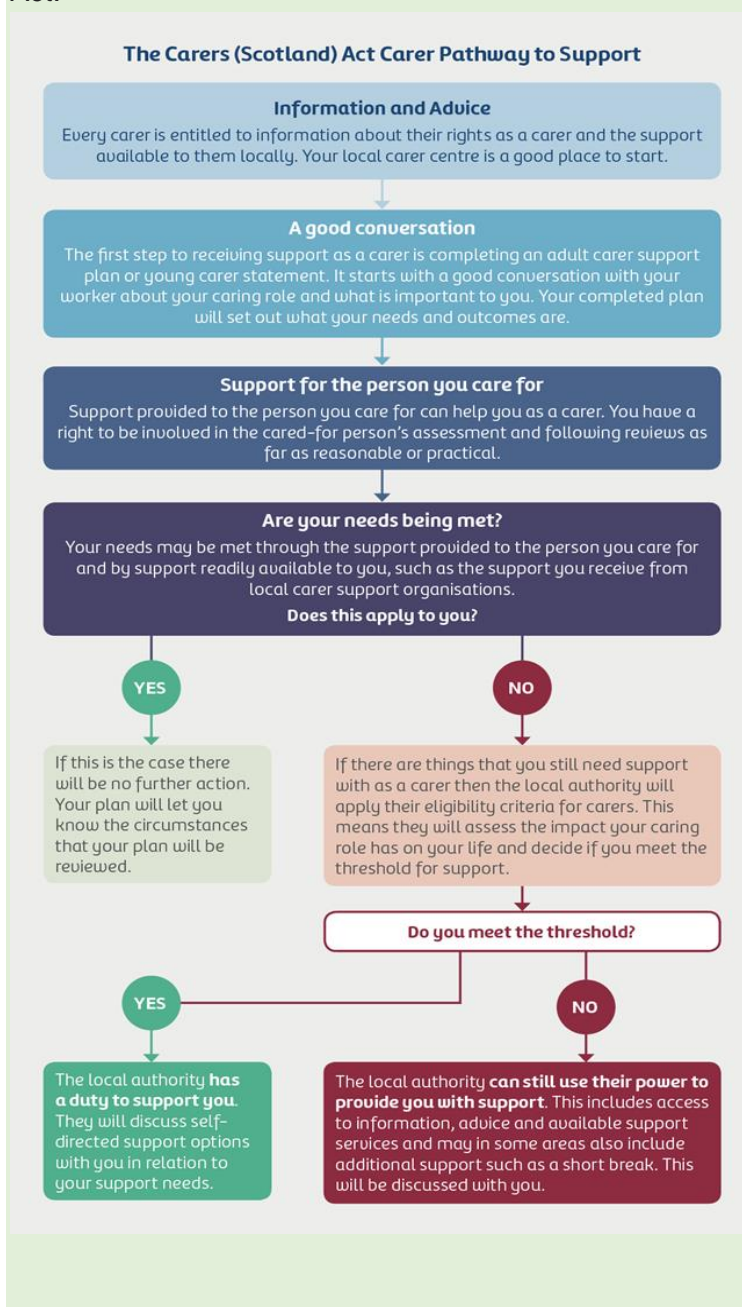
Based on the operational guidelines, a specific measure to support informal carers was included in the Social and Health Care Plan of Emilia Romagna for the years 2017-2019 and therefore included in the programmes of all the health-care Districts of the Region.

In November 2019, a resolution by the Emilia Romagna Region allocated 7 million euros to support informal carers in 2020. A group of stakeholders is currently working to facilitate the

practical implementation of the law. The first steps have been to train professionals, to dissemination about the Carers Day, to define a common template for the identification of carers, the assessment of the caregiver's needs and the indication of the services / interventions already available. Further efforts will be devoted to respite care and support around hospital discharges.

Scotland: The Carers Act (2016) enhances the rights of carers

The Carers Act became law in April 2018. It extends and enhances the rights of carers in Scotland to help improve their health and wellbeing, so that they can continue to care, if they so wish, and have a life alongside caring. Getting carer support starts with a good conversation to establish personal outcomes. Every carer will have different things that are important to them in their life. The diagram below helps to explain the carer pathway to support under the Act.



Carers have a right to an adult carer support plan which sets out information about their circumstances and caring role. It also identifies their needs as a carer and the outcomes they seek. Local authorities must provide support to any carer who has identified needs (which meet local eligibility criteria) that cannot be met through support provided to the person being cared for, or through general local services. A similar duty is in place for young carers under 18 years of age who have a right to a Young Carers Statement

Carers have a right to be involved in services. Local authorities must involve carers in:

- Planning the care services they provide,
- Assessing their needs for support and providing that support,
- Assessing the needs of the person being cared for,
- Preparing and reviewing short breaks services statements.

In addition, Health Boards must involve carers in hospital discharge arrangements for the person they care for when they are being discharged from hospital. Importantly, this law is enshrined in an approach according to which the impact of health and social care support is measured **against peoples 'personal outcomes'**.

In Scotland, carers' organisations have identified with carers eight outcomes and seek to measure the impact of all interventions and support against those outcomes. The objectives of carer support are to achieve those outcomes.

Just like any country's infra-structure of GP practices and health centres for people requiring health care, in Scotland this infra-structure provides access to information, advice, peer support and training, emotional and financial support, help with care planning and much more for Scotland's 700,000 unpaid family carers.

This is a positive example, how over just 25 years, a country has built a community based infra-structure of support which also facilitate early identification, preventative support, effective care planning and one-stop-gateways for the many areas of support carers may seek.

SWEDEN: Towards a renewed strategy to support informal carers, ten years after responsibility was given to municipalities to support informal carers?

In 2009, the Social Services Act assigned the 290 municipalities the responsibility for supporting informal carers. In 2019, the national carers' association took the initiative of a pilot study assessing how this support has been put in place locally, pointing that no follow-up of the implantation of the law had been done since 2014. The results of the study published in the beginning of 2020³⁸ shed light on discrepancies in the quality of the support provided across the country, and reveal that the resources in terms of staff allocated by Swedish municipalities have decreased. Taking stock of the shortcomings in the support to informal carers, the Minister of Social Affairs has taken initiative to shape a national strategy to better support carers.

Conclusion

Eurocarers is fully committed to the implementation of the Social Pillar and considers the Action Plan as a potentially powerful tool to advance the rights of informal carers, who mostly remain in the blind spot of public policies, be they focusing on measures or long-term reforms. While their contribution is vital to our society, informal carers are still denied their rights to equal opportunities, fair working conditions, social protection and inclusion.

Urgent action is needed in particular with regard to informal carers' rights to be protected and supported during childhood, to access training, lifelong learning opportunities and work-life balance, and to benefit from adequate income and pensions. A series of recent measures and projects illustrate possible ways forward and provide evidence for further policy developments. Furthermore, informal carers are asking that acute challenges in the area of LTC are tackled through a shared ambition at EU level, underpinned by a legislative initiative. Importantly, efforts to recognise and support informal carers across all policy areas having a bearing on their situation requires coordination through dedicated strategies at all levels.

While many of the issues related to informal care are shared across European countries, awareness and recognition of the needs of informal carers remain uneven. EU cohesion policies should ensure these discrepancies do not fuel further fragmentation within and between countries. Therefore, it will be key that all relevant financial instruments (Recovery and Resilience Facility, the future European Social Fund+ and the EU4Health Programme) are implemented in a consistent way to support progress toward carer-friendly societies. Such progress should be duly monitored through the Semester process, in cooperation with relevant stakeholders, including organisations representing informal carers.

References

- ¹ Eurocarers.(2020) [Contribution of Eurocarers to the European Commission Consultation on the Child Guarantee – Advocating for the inclusion of young carers](#)
- ² Leu A. et al. (2020) Transnational Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe
- ³ Audit Commission (2010), Against the Odds.
- ⁴ European Foundation for the Improvement of Living and Working Conditions; webpage on the topic 'NEETS' <https://www.eurofound.europa.eu/topic/neets> [accessed 19/10/2020]
- ⁵ Aidance et Emploi : une approche psychosociale des parcours et trajectoires de proches aidant.e.s, réalisée par les étudiant.e.s du Master RESPI de l'Université de Bretagne Occidentale à l'initiative d'AG2R LA MONDIALE et de l'Association Française des Aidants - juin 2020 : https://www.aidants.fr/sites/default/files/Pages/etude_aidance_et_emploi.pdf
- ⁶ Alhassan Yosri Ibrahim Hassan (2020). Challenges and Recommendations for the Deployment of Information and Communication Technology Solutions for Informal Caregivers: Scoping Review.
- ⁷ See detailed information on [Aidants Proches' website](#).
- ⁸ See detailed information on the [ONEM public portal](#).
- ⁹ Family Carers Ireland. Rights and Entitlements for Family Carer. <https://familycarers.ie/carer-supports/help-advice/rights-entitlements> Accessed 05/11/2020
- ¹⁰ [First Report of the German Independent Advisory Board on Work-Care Reconciliation](#). 2019.
- ¹¹ Strengthening Minimum Income Protection to Combat Poverty and Social Exclusion in the COVID-19 Pandemic and Beyond - Council Conclusions (9 September 2020)- 11721/20 SOC 608
- ¹² OECD (2011) Help Wanted? Providing and Paying for Long-Term Care.
- ¹³ Eurofound. (2017). European Quality of Life Survey 2016: Quality of life, quality of public services, and quality of society. Luxembourg : Publications Office of the European Union.
- ¹⁴ CNSA (2015) Rémunérations et statuts des aidant.e.s – Parcours, transactions familiales et types d'usage des dispositifs d'aide (O. Giraud et B. Rist). https://www.cnsa.fr/documentation/303-giraud-fiche_def.pdf
- ¹⁵ Eurofound. (2013). Third European Quality of Life Survey – Quality of life in Europe: Social inequalities. Luxembourg: Publications Office.
- ¹⁶ European Commission. (2008). Recommendation on the active inclusion of people excluded from the labour market.
- ¹⁷ Dr Valentina Zigante, London School of Economics and Political Science. (2018). Informal care in Europe, Exploring Formalisation, Availability and Quality.
- ¹⁸ Eurocarers. (2020). Number of carers and existing support measures across the EU. <https://eurocarers.org/about-carers/>. Accessed 15/10/2020.
- ¹⁹ Eurocarers' country profile for Estonia: <https://eurocarers.org/country-profiles/estonia>, accessed on 10/11/2020.
- ²⁰ EIGE. Webpage on poverty. <https://eige.europa.eu/gender-mainstreaming/policy-areas/poverty> Accessed on 15/10/2020
- ²¹ AGE Platform Europe (2019) [Policy Statement Closing the gender pay gap in a life-cycle perspective](#).
- ²² European Council (201). [Conclusions on Women and Poverty](#)
- ²³ High-level group of experts on pensions. (2019) [Final Report](#)
- ²⁴ European Commission (2020) [A Union of Equality: Gender Equality Strategy 2020-2025](#)
- ²⁵ Notably in the [law on pensions of 20 January 2014](#)
- ²⁶ [Programme for Government, June 2020](#)
- ²⁷ European Commission (2018). The 2018 ageing report: Economic and budgetary projections for the EU Member States (2016-2070)
- ²⁸ Rodrigues, F. H. (2010). Informal Carers: Who Takes Care of Them? Vienna: European Centre for social welfare policy and research.
- ²⁹ Eurofound (2017), *European Quality of Life Survey 2016: Quality of life, quality of public services, and quality of society*, Publications Office of the European Union, Luxembourg.
- ³⁰ EIGE. (2019). Gender Equality Index - Work-Life-Balance.
- ³¹ Eurofound. (2020). *Access to care services: Early childhood education and care, healthcare and long-term care*. Luxembourg: Publications Office of the European Union.
- ³² Jože Ramovš (2020). Summary of Findings on Modern Integrated Long-term Care Systems, Integrirana dolgotrajna oskrba. Ljubljana: Inštitut Antona Trstenjaka za gerontologijo in medgeneracijsko sožitje.
- ³³ Polley, M. 2017. Making sense of social prescribing. London: University of Westminster.
- ³⁴ Towards a caring country Policy guidelines for improving the efficiency of the Estonian long-term care system and to reduce the care burden on family members (2017) (available in Estonian [here](#))
- ³⁵ [Reducing the Burden of Care in Estonia. Interim Report. 2017. Republic of Estonia. World Bank Group.](#)
- ³⁶ Office of the High Commissioner for Human Rights. (2018) [Factsheet No 33: Frequently Asked Questions on Economic, Social and Cultural Rights'](#)

³⁷ Regional Law n. 2, 28th march 2014.Regulations concerning the recognition and support of the family caregiver (a person who voluntarily provides care and assistance) <http://sociale.regione.emilia-romagna.it/documentazione/norme/leggi/successivi-il-2010/lr-2-2014-1>.

³⁸ [Anhörigperspektiv - en möjlighet till utveckling?](#) 2020 Anhörigas Riksförbund