

ANNUAL REPORT

2021

**Heading towards an EU Strategy
on Care that recognises,
identifies and supports all
unpaid carers across Europe**

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Eurocarers receives support
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Forewords

Dear friends and colleagues,

The period 2021-2022 has been a period of reflection and rejuvenation, following the unprecedented crisis caused by the COVID-19 pandemic. While we are not entirely out of the woods yet, the last two years have led the general public to realise that care and caring are among the binding forces of cohesive, inclusive and sustainable societies. As with any good crisis, the pandemic has been useful to test our resilience, to identify our weaknesses and – hopefully – to build back better and stronger. In this context, I am pleased to report that, since 2020, our message on the many challenges faced by informal carers has drawn more attention and interest than ever from decision makers and stakeholders across Europe.

As a result, and as this report shows, the EU and national policy environment in which we operate continues to evolve towards a more carer-friendly configuration – although slowly. The upcoming launch of an EU Strategy on Care, announced by President Von der Leyen in September 2021, is the latest and most exhilarating indication of our movement's gradual progress. The Strategy generates a lot of hope and enthusiasm among civil society organisations and, in our view, it may prove a powerful instrument to coordinate Member States' efforts as they try to meet the growing care needs of the European population. More importantly, it can also serve to drive a more equitable distribution of caregiving responsibilities between the family and the State, care professionals and informal carers, as well as women and men. Naturally, this will call for urgent policy steps at all relevant levels to reinforce our professional care systems (by making the profession more attractive, for example) but also to recognise, identify and support all unpaid carers throughout Europe.

Besides these policy opportunities, the pandemic has also proven that NGOs do not need a formal contractual framework to respond to the needs of the community. Many of our member organisations have indeed stepped in to offset the interruption or reduction of services (when in existence) in their country or region, by providing access to PPE, information, self-help groups,

psychological/emotional support, counselling, care coordination and administrative support. To do so, many have shown inventiveness and strength in the face of a sometimes-adverse context. So, as always, I want to conclude by thanking them for their tireless efforts to ensure that no one in Europe has to face poverty, social exclusion, bad health or discrimination as a price for their solidary and support towards a loved one in need of care. This, to me, is what Europe is about!

Stecy Yghemonos - Executive Director



Forewords

Since 2020, we have had to co-exist with COVID-19. As a result, numerous carers and care recipients have suffered the disease and many - usually among the most vulnerable citizens - have lost their life because of it. The pandemic continues to put the resilience of informal carers and the agility of family care organisations to the test. But the crisis has also led the European Commission to acknowledge family carers and Eurocarers' national member organisations as important actors in the care provision. Our organisation was indeed thrilled to learn about the announcement of a future EU Care Strategy. As always, we will collaborate with all relevant partners and will do our best to make the strategy a success.

In 2021, the entire Eurocarers network successfully celebrated the 2nd European Carers Day. When uniting our forces, we are stronger in our advocacy messaging. Campaigning allows to shine a light on informal carers' needs and it increases the political pressure for carers rights. I encourage all of us to redouble our efforts to ensure an even more powerful campaign in 2022, on the topic of Gender equality and caregiving.

Eurocarers would not be the impressive network it is today without the continuous determination of our members. I would like to acknowledge all of our colleagues across Europe for their activities at local, national and European level. I would also like to express my gratitude to the Eurocarers Board and Secretariat for another remarkable year. Finally, I would like to thank the European Commission and our partners for their financial support to the mission of Eurocarers.

Informal care is both a very personal experience and a hot political topic. The consequences of the ageing demographic we have been experiencing in the last decades lead to a growing number of daily challenges for carers, mainly because of a lack of practical help and services. While informal care is part of the solution to the rising demand for care, it is very clear that carers should and will not contribute at any cost. Basic human rights also concern informal carers and Eurocarers therefore remains committed to promoting a healthier and more equal future of all informal carers.



About us

Eurocarers is the European network representing informal carers and their organisations, irrespective of the particular age or health needs of the person for whom they care. Our network brings together 75 carers' organisations as well as relevant research & development organisations in 26 countries – a combination that enables evidence-based advocacy. These organisations are active at international, national and regional level. An overview of our membership is available on our website: <http://www.eurocarers.org/membership>.

Eurocarers is designed as a platform for collaboration, support, exchange, awareness-raising and policy change. Our collective efforts seek to ensure that the existing and growing care needs of an ageing European population are addressed in a universal and equitable way and that the essential contribution of unpaid/informal carers in the provision of care is valued and recognised as central to the sustainability of health and long-term care systems, and supported to prevent the negative impact of care on carers themselves. We believe that carers' know-how and needs are worth listening to and that people should have the right to choose freely whether they want to be a carer, and to what extent they want to be involved in caring.

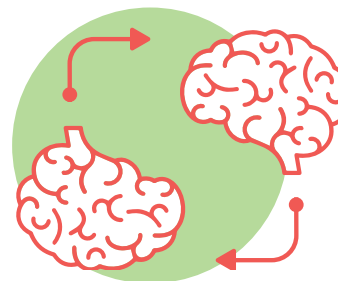
The mission of the Eurocarers network is therefore to act as a voice for informal carers by:



Documenting and raising awareness about the significant contribution made by carers to health and social care systems and the economy as a whole, the impact of caring on carers' ability to maximise their life prospects and maintain an active and productive life, as well as the need to address the daily challenges facing carers across Europe;



Contributing to evidence-based policy development at national as well as European level that take account of carers, i.e. promote their social inclusion, the development of support services, enable them to remain active in paid employment and maintain a social life; and



Promoting mutual learning and an exchange of good practice and innovation throughout the EU.

Policy environment

The boosting impact of Europe's demographic ageing and increased longevity on the prevalence of chronic/age-related diseases and the demand for care is well documented. Yet, over the last decades, the care sector has suffered from underinvestment, mismanagement, poor job quality (i.e. low pay, difficult working conditions, limited career prospects) and - as a result - low recruitment and retention rates as well as shortages in both the health and social care workforce. According to a recent study, the EU-27 will need 11 million newly-trained or imported health and long-term care workers by 2030 to satisfy the rising demand in these sectors. These trends reveal serious sustainability and quality challenges for our care systems. They are also compounded by the pressure generated by the pandemic as well as by the often-inadequate training of many personal care workers who account for 67% of the long-term care workforce in the EU, are not qualified or certified as nurses and yet often participate in the implementation of care plans and maintenance of health records. These trends and challenges can be observed across EU member states who must address them as a matter of priority if we are to safeguard the principle of universal access to care in Europe.

As it stands though, the lion's share of all care in the EU is provided by relatives, friends and neighbours - and women in particular - outside of a professional context and with extremely limited recognition or support. The value of these informal carers' contribution to our care systems and the economy as a whole is so significant that it is practically impossible to replace informal by professional care, at least in the foreseeable future. But the provision of informal care does not come without a cost for carers themselves.

Without proper support, many are indeed faced with additional expenditures as a result of the condition of the person for whom they care, and their caring responsibilities can be a barrier to entering education and paid employment. Working carers often have to perform a difficult balancing act and may be forced to reduce their working hours (involuntary part-timers) or drop out of the labour market, thereby reducing their income and pension entitlements. The gender dimension of this phenomenon is particularly clear.

The correlation between caregiving and physical/mental health issues is also well established. Research has highlighted that the pressure associated with informal caregiving presents all the features of a chronic stress experience: it creates a physical and psychological strain over extended periods of time, it is accompanied by high levels of unpredictability and uncontrollability, it frequently requires high levels of vigilance, and it has the capacity to create secondary stress in multiple life domains.

The negative consequences of informal care on carers' working and living conditions can also be observed in all member states and our recent study on the impact of COVID on carers shows that these pre-existing challenges have been greatly amplified by the pandemic, with carers providing more care, more intense care and with a new population of carers emerging from the crisis.

Against this backdrop, it is very clear that professional and informal care are two sides of the same coin and that the current situation calls for an urgent and vigorous policy response. Unpaid care activities have been left out of policy agendas for too long and our "new normal" shows how this omission has limited policy effectiveness across a range of socio-economic areas.

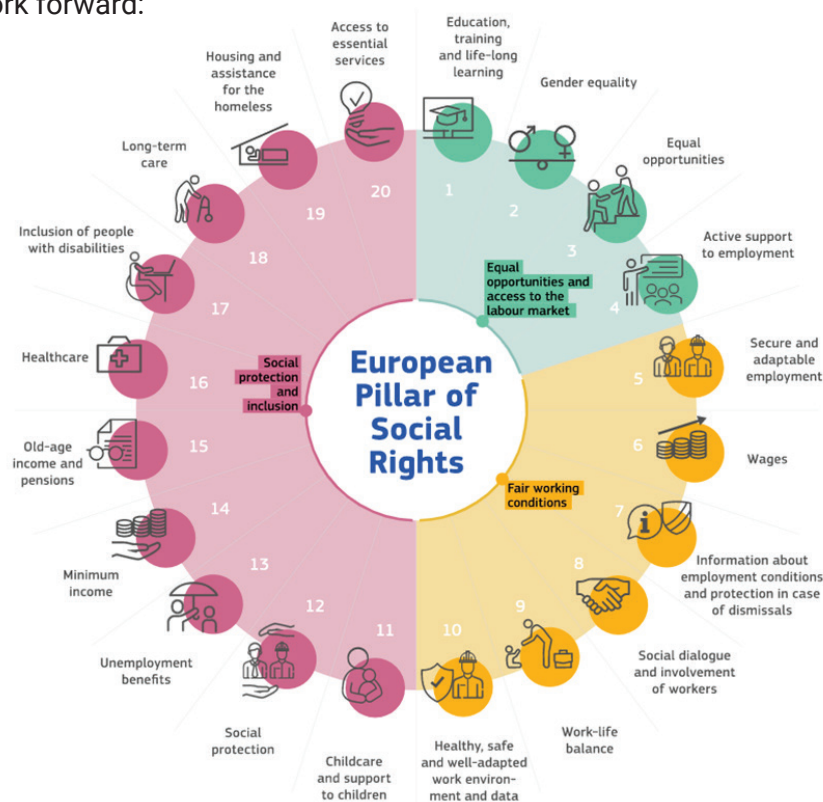
While care should be considered a key driver of our societies' wellbeing, the allocation of caregiving responsibilities between the family and the State as well as between men and women must be revisited in order to foster equality and equity, to protect carers and care users' freedom of choice and to prevent discrimination for all.

It is therefore imperative for governments to alleviate the reliance on informal carers while recognising and supporting their essential contribution, provided that it is based on choice and free will (i.e. not dictated by necessity). People should have the right to choose whether they want to be - and remain - a carer, and to what extent they want to be involved in caring. In contrast, people who do NOT want - or are not able - to be involved in the provision of care to their relatives or who only want to play a limited role in these activities should be able to access affordable and professional care alternatives of good quality,

Policy environment

and in particular home-care and community-based services. In other words, informal care should supplement professional care, not the other way round!

While the competence for the design and implementation of policies with an impact on the daily life of informal carers mainly lies at national level, a wide-ranging coordination process at EU level can serve to develop common approaches, monitor progress, foster an exchange of information and good practices and complement national efforts. The idea is of course not to put the exact same support measures in place across the EU but to encourage all member states to work towards the same objectives on both formal and informal care. Here are some of the EU instruments used by Eurocarers to take our work forward:



The **European Pillar of Social Rights**, endorsed by EU institutions and member states in November 2017, recognises the need to act proactively in order to reinforce social cohesion across the EU. In that context, the Pillar approaches adequate social protection as a productive factor and social convergence as a necessity. It builds on the idea that more cohesive countries perform better in difficult times. The Pillar therefore sets out 20 key principles and rights that are seen as essential for fair and well-functioning labour markets and social protection systems. In 2021, the European Commission published an Action Plan to help member states as they seek to operationalise the Pillar. The Plan also proposes headline targets for the EU to reach by 2030.

at least
78%
of the population
aged 20 to 64 should
be in employment
by 2030

at least
60%
of all adults should
be participating in
training every year
by 2030

a reduction of at least
15 million
in the number of
people at risk of
poverty or social
exclusion

Most of the 20 principles of the EU Pillar of Social Rights are in direct resonance with the many facets of the informal care challenge and Eurocarers' mission. As a result, the Pillar provides a great environment for the work of our organisation and a wonderful opportunity to promote our proposal for a coordinated and multidimensional approach to care and caring – i.e. an EU Strategy. The latter would indeed allow to connect the dots between existing policy initiatives of relevance to carers and identify remaining gaps.

The principles of the Pillar that concern access to health and long-term care are natural entry points for all our activities. We therefore continue to support EU institutions (and member states) in the development of a common approach to long-term (and informal) care and in the collection of better and more comparable data about access, quality and sustainability of care and caring in Europe. Other principles of the Pillar nevertheless form

Policy environment

part of our portfolio of work. For instance, our network continues to closely monitor the implementation of the **Work-life Balance Directive for parents and carers**, as illustrated by our position paper published in 2020. The themes of inclusive education, gender equality and equal opportunities remain equally important to promote the best interest of all informal carers in Europe, given the demographics of that group (which is mainly composed of women, with largely invisible components among younger people). By extension, many associated EU or EU-sponsored initiatives are targeted and informed via our policy, research and communication activities and our partnership with EU institutions. These include the Green Paper on Ageing, the work of the Social Protection Committee, the Ageing Report 2021, the EU Gender Equality Strategy 2020-2025, the EU Beating Cancer Plan, the UN Convention on the Rights of Persons with Disabilities or the EU Blueprint for a digital transformation of health and care, among others. We are glad to report that they all recognise the need to support informal carers as a result of our work!

Given their importance in our work, the online meeting of the **Eurocarers Policy Working Group (EPWG)**, held on the 16th March 2021, served to discuss the potential offered by the Pillar's 20 principles. The Group is an important vehicle to enable our Secretariat and member organisations to identify promising/challenging policy initiatives and support measures at EU, national and local level and to align our advocacy strategies to maximise the impact of our collective and respective work.

The EPWG meeting specifically focused on:

- Recent EU policy developments of relevance to our work, including Europe's Beating Cancer Plan, the New EU Disability Strategy 2021-2030, the Strategy on the Rights of the Child and European Child Guarantee, the Committee of the Regions' consultation on a 'Future plan for care workers and care services', and the EC Consultation on the Green Paper Ageing, Action Plan for the implementation of the EU Pillar of Social Rights; and

- Key priority areas for the next steps of our work programme, i.e. the reintegration of informal carers in society/employment after a period of care and grief, Informal carers' access to training and skills validation; carers in assisted decision-making process and other guardianship arrangements; and loneliness.

The meeting brought together by 31 participants from 22 organisations in 17 countries.

On the 15th September 2021, EC President Ursula von der Leyen announced that the European Commission will put forward a new **European Care Strategy** as part of its Work Programme 2022 in order to "support men and women in finding the best care and the best life balance for them". Ms. Von der Leyen added that "caring for someone you love is the most precious time of all" thereby suggesting that it may be time for care to be properly valued and supported across the EU.

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Caring for
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of all
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Policy environment

This much-welcome and very timely initiative has the potential to generate positive developments for an under-resourced and overburdened care community. Moreover, it is expected that the Strategy will seek to address both the formal and informal provision of care in Europe and will be an integral part of the implementation plan of the European Pillar of Social Rights. At this stage, its intended objective is to ensure that care recipients have access to good-quality services and that informal/unpaid carers receive the support they need to prevent the negative impact of their caregiving. This approach is very much in line with the vision promoted by Eurocarers since its creation in 2006, around the need for a comprehensive concept of care, rooted in human rights, choice and dignity for both care users and their carers.

The EU Care Strategy can prove an essential tool to meet the growing care needs of the European population and strike an adequate balance between professional and informal care in Europe. As explained above, both aspects are closely intertwined and are essential to formulate a comprehensive answer to the European care challenge.

Just a few years ago, the idea of a coordinated EU dialogue on long-term care seem far-fetched to say the least. But the COVID-19 crisis has contributed to a dramatic change of mindset and has led to the realisation that care and caring have served to bind societies together in the the last few years. The announcement of an EU Care Strategy therefore demonstrates that our movement can be carefully hopeful about the future. Having said that, big expectations may lead to equally big disappointments. So, the Eurocarers network will continue to advocate for all informal carers in Europe and inform the debate with evidence-based recommendations.

From our viewpoint, the EU Care Strategy should seek to:

- Introduce EU-wide indicators as well as ambitious targets regarding access to long-term care;
- Define a quality framework for care services rooted in human rights and focused on people's preferences, dignity and quality of life;
- Enhance the development and implementation of integrated community-based care, which is a root cause of many of the challenges facing member states as regards quality, sustainability and unmet care needs. The lack of alternative solutions is also one of the main predictors of the prevalence of informal care, which is too often seen as the default option for the provision of care in Europe. It is therefore essential to boost developments in that sector; and
- Encourage EU member states to develop a legal recognition of informal carers, which should be accompanied by rights (e.g. access to social protection, financial support, pension, respite care, information and training) as well as obligations (in terms of care quality criteria, for example).

Eurocarers' instruments for Policy change

The mission of our secretariat is to lead and support evidence-based dialogues aiming to build bridges between carers, academics and policy makers and to inform EU and national policy developments on how recognising and supporting the contribution of carers can benefit European societies. Our positioning as a respected source of information regarding care and caring in Europe has allowed us to play a part in relevant policy debates with the EU institutions (European Parliament, European Commission, Committee of the Regions and European Economic and Social Committee) and a broad variety of stakeholders (WHO, OECD, Civil Society Organisations, private sector); as well as through a series of advocacy activities and tools, which – in 2021 - included 4 Policy briefings as well as 15 position papers and Consultation responses (see details below).

The development of a care(r)-friendly policy environment largely depends on the relationship between a broad set of policies and practices in the social, health and employment sectors (among others). It is therefore important for Eurocarers to organise and take part in outreach events, policy dialogues, scientific conferences, exhibitions, etc. at EU and national level. These networking activities allow us to build synergies, foster cross-sectoral cooperation and convey our message on the opportunities and challenges offered by EU (and national) policy instruments to a large audience. In 2021, Eurocarers played an active role in more than 180 events focusing on our 'natural' entry points in the policy agenda (e.g. EU Semester/Recovery and Resilience Facility, EU Pillar of Social Rights, SPC, etc.) as well as on (mental) health, disability, youth, gender equality, ICT and equal opportunities. As always, this gave us a chance to reinforce our sphere of influence, connect the dots and contribute to a "care in all policies" approach.

The Policy Briefings developed by our network in 2021 explored:

- The EC/EP proposal on an EU Care Strategy (and what we expect from it);
- The potential offered by ICT-based solution for Carers, with a section on the factors influencing carers' use of ICT;
- Gender Equality and care; and
- Our analysis of the EU Recovery and Resilience Facility.

Our Overview Table on the Number of carers and existing support measures across the EU and our 27 Country Profiles were updated based on our desk research, our continuous data collection and dialogue with/via our network as well as our networking activities. These serve as monitoring tools to keep track of recent advances made at international, national and regional level with regard to our overall mission. The table and country profiles are structured around the 10 steps of our proposed EU Carers Strategy. They are accessible via our website (see <https://eurocarers.org/about-carers/> and <https://eurocarers.org/country-profiles/>).

The 27 country profiles also feed into the work of our member organisations at national and regional level, the narrative developed around our European Carers Day campaign and the discussions held during our capacity-building and coordination activities (working group meetings, knowledge-sharing seminars, AGM, etc.)

In 2021, Eurocarers also (co-)developed and disseminated new position papers and consultation responses in order to inform international and national policy developments, including on:

- The OECD work on the introduction of a cash benefit for informal carers in Croatia;
- The Committee of the Regions' consultation on "Future plan for care workers and care";
- The draft EP report "New Avenues for Legal Labour Migration";
- The EU consultation on the Green Paper on Ageing;
- The draft EC/SPC report on Long-Term Care;
- The White Paper on the impact of cancer-related co-morbidities on patient treatment, treatment efficacy, survivorship, and quality of life;

Eurocarers' instruments for Policy change

- The Impact of the COVID-19 outbreak on informal carers across Europe;
- The study paving the way for a possible EU initiative on Long-Term Care;
- The EP Report on an old continent growing older;
- The Consultation on EU4health-related priorities, strategic orientations and needs;
- The EP Report on Strengthening Europe in the fight against Cancer;
- Reinventing primary health care in the post-COVID-19 era (at the 71st Session of the WHO Regional Committee for Europe);
- International Standards on carer-inclusive and accommodating organisations (ISO 25551:2021); and
- The Spanish national consultation on the reform of the dependency law.

The European Parliament's Interest Group on Informal Carers is one of Eurocarers' main instruments to contribute to policy change at EU and national level. The role of the Interest Group is indeed to monitor and analyse EU policy development for its impact on carers and to propose and advocate concrete action in order to improve the day-to-day situation for Europe's many carers, working in close partnership with relevant stakeholders. The Group currently brings together 28 MEPs interested in care and caring from 11 countries and 5 EU political groups (S&D, EPP, Renew, GUE/NGL and the Greens). Two meetings of the Interest Group were convened in 2021.

The first meeting took place on the 23rd February 2021, on the theme 'Towards an ambitious EU initiative on long-term care', with 66 participants in attendance. The meeting was used to define the aspects that the future European Care Strategy should seek to address, namely:

- The collection of good-quality data, which is crucial to have a clear picture of the current situation care and caring and to pilot the Strategy;
- The implementation of the EU Directive on Work-Life balance, which is essential for the success of the Care Strategy considering the importance of gender aspects in care and caring;
- Good working conditions for both formal and informal carers. In this context, access to decent wages, social welfare and pension rights are crucial;
- The development of a strong care infrastructure: Europe is currently losing trillions of euros because of the untapped potential of many citizens;
- Funding: never before has Europe made so much money available to Member States (via the Recovery and Resilience Facility). Investment in care systems should be at the core of national action plans; and
- Setting targets: measures and targets should be introduced in relation to access, quality and sustainability of long-term care.

The second meeting of the EP interest group on carers was held on the 28th September 2021 on 'the impact of COVID-19 on Informal carers. It brought together 85 participants. This meeting served to share the outcomes of Eurocarers' study on the impact of COVID on carers and highlight the increasing policy interest in long-term care and carers. It also focused on the EPP initiative on a European Care Strategy and explored possibilities for EU action to increase concrete policy attention for LTC/carers across the board.

Capacity Building

Knowledge-sharing seminars

Our “knowledge-sharing seminars” serve to generate an exchange of views and good practices among our members and partners in the areas of policy, research and communication. The themes of these events directly proceed from our members’ interest and needs and is therefore selected by our network. They usually relate to existing EU priorities and decision-making mechanisms, such the EU Semester process, the EU Pillar of Social Rights or any other tool potentially useful to help our members in their own advocacy work at national and local level. Our seminars (or webinars) traditionally take place in the margins of our Annual General Meeting. The co-operative implementation of the EU Social Pillar and our proposed European Strategy on Carers; measures to facilitate the transposition of the Strategy at national and regional level; our collective activities to document the needs and situation of carers across Europe as well as our work to monitor the transposition of the Work-Life Balance Directive (among others) all form part of these discussions.

In 2021, our knowledge-sharing seminars focused on:

- The learnings of our Survey on the impact of COVID-19 on carers: this session allowed to share and discuss the results of our EU-wide study, which builds on the direct experience of 2500 informal carers in 16 countries. The study was conducted by Eurocarers in close collaboration with one of its Italian members, the National Institute of Health and Science on Ageing (IRCCS/INRCA).
- European Carers Day 2021 - Planned communication strategy and next steps: following the launch of our European Carers Day (ECD) campaign in 2020, at the height of the pandemic, ad-hoc coordination activities have been organised with our network in the field of communication (e.g. mailings, newsletter items, dedicated briefing calls, consultation process on ECD communication material, etc.) This session served to discuss our plans for the second ECD, on the theme of young carers, with our membership. More importantly, the session allowed to present the policy context for the campaign (EU strategy on the rights of the child, Recommendation for a European Child Guarantee, etc.) and exchange on respective plans and priorities at national/regional level.

Capacity Building

Study Visit

Eurocarers' study visits provide opportunities to highlight specific entry points that exist in the EU/national agendas and allow interested member organisations to exchange on their views, experience and expertise (including through existing good/promising practices) with regard to these policy hooks. Given the continuous constraints imposed by COVID-19, our study visit 2021 was converted into a webinar, held on the 26th October on the theme "Ensuring carers' access to an adequate income". The event brought together representatives from 13 organisations in 10 countries. The discussion focused on possible measures to ensure income replacement for carers, reintegration in employment, pension rights as well as other income-related issues (for example, the financial toxicity of care). The topic was suggested by Eurocarers members themselves via a consultation survey and on the basis of our Policy Working Group's preparatory work.

The webinar's specific objectives were therefore to:

- Facilitate an exchange of information and mutual learning between members;
- Reinforce individual members' capacity to develop relevant projects and advocacy strategies in their country/region;
- Develop an overall understanding of the issues at stake across Europe and strengthen Eurocarers' messaging;
- Reinforce our capacity as a European network to influence EU policy making on these issues in the months ahead.

Capacity Building

Action at national and regional level

Positive developments continue to be observed across member states as a result of our work with EU institutions and relevant stakeholders. In the last few years, a growing number of countries have started to equip themselves with (some of) the tools required to meet the needs of informal carers and prevent the negative impact of caregiving on their social inclusion and access to employment. For instance, new legislation and support measures have been introduced in Belgium, France, Germany, Ireland, Italy, Portugal, Sweden, Norway or the UK – among other countries. It goes without saying that Eurocarers will continue to support and keep a close eye on all of these developments. Naturally, we will also seek to foster new and further developments in all European countries (not least because our members and partners are often actively involved as well in the design and materialisation of these developments).

In-country policy dialogues on situation and needs of carers

In order to facilitate this process, each year, the Eurocarers Secretariat regularly teams up with member organisations to co-organise national/regional events aiming to generate a dialogue with decision-makers from the health and social sectors on the situation of carers and ways of supporting them, building on the European Pillar of Social Rights and EU Semester/Recovery and Resilience Facility.

These “in-country policy events” aim to:

1. Raise awareness on the situation and needs of carers and contribute to the development of new national/regional initiatives on care and caring, in accordance with the 10 steps of our proposed EU Strategy on carers, and

2. Contribute to better synergies between EU objectives (in particular, the principles of the European Pillar of Social Rights and the European Semester) and national/regional policy agendas around integrated and multidimensional approaches to care and caring.

In 2021, Eurocarers co-organised/contributed to five national/regional policy dialogues, namely:

- The 5th Caring for carers conference on the topic “Balancing the Personal and Professional Life of Carers in the COVID-19 Era” held in Athens, Greece on the 24th September 2021 and organised by EPIONI, the Greek organisation of carers (as a hybrid event), under the auspices of the Municipality of Vouliagmeni and in collaboration with the Hellenic Psychiatric Society.
- The Meeting of the Finnish Family Care Parliament and 30-year Anniversary event of Carers Finland on the 6th October 2021 (European Carers Day), with the participation of Ms. Krista Kiuru, Minister of Family Affairs and Social Services, MPs Merja Kyllönen and Mia Laiho, as well as experts of the Central Organisation of Finnish Trade Unions, Finnish Confederation of Professionals, University of Tampere and Department of Health and Welfare.
- The 3rd National Meeting of Informal Carers, organised by the Portuguese Association of Informal Carers on the 5th November 2021 (i.e. Portuguese Carer Day). The meeting focused on the recently-created regulation of the Informal Caregiver Statute and its transposition at regional level.
- The 23rd Swedish Carers Day, organised by Carers Sweden, held on the 9-10 November 2021 (as a hybrid event) at the Karlstad Congress Culture Centre. The event focused on “Informal carers across time” and allowed to shed light on various dimensions of care, including the (mental) health of carers, men in care, carers’ experiences during the pandemic, palliative care or the future of care.

Communication

European Carers Day

The second **European Carers Day (ECD)** campaign was held on (and around) the 6th October 2021. The campaign forms part of our general communication strategy ("European Carers Awareness campaign"). It is implemented in close collaboration with our member organisations and it aims to coordinate/nurture national awareness-raising efforts on the Carers' issues under a pan-European structure. The specific objectives the European Carers Day campaign are to:

1. Foster a feeling of community among carers organisations rooted in internal unity, communality of vision and a clear direction to inspire action;
2. Raise public awareness about carers' role in society: a wider-reaching European campaign will have the ambition to inspire local, regional, national and European action, therefore creating a grassroots movement supporting caregivers; and
3. Achieve policy change: by directing common efforts towards policymakers across the European Union, the campaign will ultimately contribute to ensuring that the needs of carers are mainstreamed into social, employment, health and equal opportunities policies at the EU level and national strategies supporting carers are enacted at the member state level. This will build on our uninterrupted call for more investment in formal care and on the 10 steps of our EU Carers Strategy 'Enabling Carers to Care'.

ECD is therefore a continuous effort with peak activity revolving around the 6th October of each year and specific themes selected by our network on a yearly basis. The theme selected for this second European Carers Day campaign, was "Identifying, listening to and supporting young carers".



Communication

The focus on young carers was driven by various reasons:

- The scale and importance of the issue - although there are no accurate figures on the number of young carers across Europe, Eurocarers estimates that about 7-8% of children in Europe have caregiving responsibilities. These are children who largely remain invisible to public authorities, social policy and interventions from health and social care services and are therefore at high risk of adverse outcomes. Being an adolescent young carer, for example, is recognised as a risk factor for negative mental health and well-being, with around 50% experiencing care-related stress and 40% mental health problems;
- The possibility to build on Eurocarers' past successes and efforts - Eurocarers has been very active on the issue and our engagement with EU policy makers and stakeholders has already proven fruitful. For example, the need to pay attention to young carers was included in the recommendations of the EP report on "Care Services in the EU for Improved Gender Equality" and clear reference to young carers was added to the European Network of Ombudspersons for Children's statement on child mental health, as a result of our work;
- Our network's in-house expertise on the topic is well developed and we have already produced extensive analyses, recommendations and material, such as the 2017 'Policy Paper on Young Carers', which could form the basis of further investigation. Eurocarers has also played a leading role in various EU-funded research projects on the topic, as described in the research section of this report.

The communication toolkit prepared by the Eurocarers Secretariat (i.e. posters, press releases, call to action, social media posts, etc.) was translated into 11 languages and disseminated across our network. ECD 2022 was piloted with the keen contribution of our Young Carers Working Group whose members were also actively involved in the preparation and implementation of the 3rd International Young Carers Conference (see details below). The campaign drew quite a lot of attention and interest on the social media, with substantial visibility in Belgium, Finland, France, Greece, Italy, Norway, Portugal, Scotland, Slovenia, Sweden and Switzerland.



Communication

Third International Young Carers Conference (IYCC)

The third International Young Carers Conference (IYCC), was co-organised with Linnaeus University and held virtually on the 3-6 May 2021. The aim was to contribute to increased awareness, new policy dialogues and improved support measures targeted at young carers by bringing the issue forward at national and international level. The event brought together more than 300 participants (Researchers, practitioners, policy-makers and young carers) from 26 countries (including Canada, USA, Iceland and Japan). Naturally, young carers themselves played a leading role in the event. The theme of the conference itself - "Identify, support and listen to young carers" - as well as the programme of the event had been selected with the active involvement of our Young Carers Working Group.

Besides the presentation of numerous research projects and good practices from across the globe, the IYCC programme gave an opportunity to hold inspiring and promising policy dialogues. One of these, held in plenary session, brought together various policy makers (i.e. an Italian MEP, Ms. Elisabetta Gualmini, a representative from the Swedish National Board of Health and Welfare, a representative of the Dutch Ministry of Health, Welfare and Sports as well as a British MP) and young carers from Italy, Sweden, the Netherlands and the UK. The session gave an opportunity to map out existing policy interventions and support measures targeted at young carers at international, national and local level as well as gaps to be filled in the future.

The IYCC also benefitted from the contribution of Commissioner Helena Dalli who opened the event, Ms. Lena Hallengren (Swedish Minister for Health and Social Affairs) who gave a keynote address, as well as Ms. Valeria Setti (EC Coordinator for the Rights of the Child), Ms. Niall Muldoon (Irish Ombudsman for Children), Ms. Jana Hainsworth (Secretary General of Eurochild) and Ms. Ramya Subrahmanian (Chief of Child Rights and Protection at UNICEF-Innocenti) who played an active role in panel discussions.



Our Research Work

Research Working Group

The mission of the Eurocarers Research Working Group is to inform evidence-based practice and contribute to the wider EU-level research agenda in the areas of care, carers and caring. In 2021, the aim of the meeting was to identify current research priorities, including gaps in knowledge and scientific challenges and provide evidence and analysis in order to help inform EU policy-making.

In 2021, our Research Working Group held two (online) meetings. The first took place on the 16th June and brought together 39 participants from 33 organisations in 19 countries. The meeting focused on the recently-initiated research study on “Models of Family Carer Support During Covid-19”, funded by the Irish Health Research Board, existing criteria and methodologies to define and measure informal care, the InCare project (funded through the EaSI programme) as well as opportunities for future research work.

The meeting also gave the Eurocarers secretariat a chance to provide information about the state of play of our organisation’s work on an EU Strategy on care and caring (with the EP and EC) and around the recently-published SPC/EC 2021 Long-Term Care in Europe report.

The second meeting of the group took place on the 26th November 2021, with 28 participants from 24 organisations in 16 countries in attendance. It provided Eurocarers members with an opportunity to exchange on respective research activities and learnings, develop synergies, discuss priorities for future research and identify funding opportunities, as always. More specifically, the exchange allowed to learn and discuss on:

- The ongoing EIGE-funded study on Gender gaps in unpaid care;
- The Results of Me-We project on young carers (Horizon 2020) and cost of informal care and research translation activities in Sweden;
- The Danish Construct of care;
- Morbidity in Finnish caregivers;
- Addressing the Experiences of Family Caregivers of Older Caregivers;
- Online training for carers in France;
- The impact of COVID on carers in Hungary, Slovenia and Italy; and
- Predictors of Digital Support Services Use among carers.

Our Research Work

Young Carers

Nothing about young carers without young carers! This was the primary drive behind the creation of the Eurocarers Young Carers Working Group (EYCWG), back in May 2017, in the framework of the 2nd International Young Carers Conference held in Malmö, Sweden. By then, young carers had remained in the blind spot of policy makers for way too long and it was high time they were given the attention and respect they so rightly deserve. With this in mind, the aim of the working group is to combine efforts and resources, so that young carers' voices are heard and policies and practices, infused with their first-hand experiences, are put in place all across Europe to support them. As it stands, the group benefits from the involvement of more than 30 young carers, young adult carers or former young carers from 11 countries.

The meeting of the EYCWG took place on the 25th February and focused on the programme, logistics and role to be played by young carers during the Third International Young Carers Conference. It also gave an opportunity to discuss and co-design the message to be conveyed at the occasion of European Carers Day 2021 (see above). The event brought together 18 members of the working Group.

Besides the work of our dedicated Young Carers Working Group, the Eurocarers network has played an active role in research projects seeking to document the situation and needs of young carers, thanks to the support of the EU under the Horizon 2020 and Erasmus+ programmes.



Me-We (Psychosocial Support for Promoting Mental Health and Well-being among adolescent Young Carers in Europe / 2018-2021) is a project funded through the Horizon 2020 programme, which was completed in June 2021. Me-We aimed to mitigate the risk factor of being an adolescent young carer by empowering the young with improved resilience and enhanced social support (from family, schools, peers, services). More specifically, it sought to systematise knowledge on adolescent young carers, co-design, develop and test - together with adolescent young carers - a framework of effective and multicomponent psychosocial interventions for primary prevention, and to carry out wide knowledge translation actions for dissemination, awareness promotion and advocacy.

Me-We produced quite a few important outputs, including: new data about the prevalence of informal care among adolescents in Europe; a series of policy briefs (Italy, Netherlands, Slovenia, Sweden, Switzerland, United Kingdom and Europe) to provide a national perspective on the learnings of the project; a booklet developed with and for young carers offering practical support in the areas of health and wellbeing, education-care balance, management of bullying, etc.; a manual for multi-stakeholders' actions aiming to fill the knowledge gap and inform multidisciplinary action (e.g. by policy makers, health and social care providers, school professionals, youth, care workers, the media and the general public); and a final report presenting a comprehensive transnational comparison of the legislation, policy and service frameworks that exist to protect and support adolescent young carers in six European countries (Italy, Netherlands, Slovenia, Sweden, Switzerland and the UK).



me-we.eu/internal-resources/

Our Research Work



Together - Support social inclusion and engagement of young carers by adopting a whole family approach

The TOGETHER project aims to support social inclusion and engagement of young carers in Germany, Italy, Greece and UK by helping young carers and care professionals to adopt a whole-family approach, where members of the household are encouraged to communicate openly about the illness and caring needs; the condition of the care recipient is explained clearly to the younger members of the family; and relationship building within the family is supported.

The ultimate goal of Together is to have an impact on families where caring responsibilities exist and where children/adolescents are present, so as to prevent/reduce the negative impacts on them and to improve their wellbeing, social inclusion and community engagement. To that end, the project consortium has developed awareness-raising material on the whole-family approach targeted at young carers, a training seminar for young carers and their significant adult, and an online training curriculum for professionals on the Together model.

ICT based solutions for care

ICT-based solutions for care and caring can greatly benefit the social integration of carers, provide them with the social, emotional and peer support they need, facilitate their participation in aspects of life outside the home and improve their quality of life. Our network is therefore involved in research and innovation projects aiming to develop new technology-enabled solutions in favour of carers and care recipients.



The **MATUROLIFE** project is a 3-year project funded through the Horizon 2020 programme which has developed enhanced assistive technology products for older adults (based on smart metalized textiles), to make older persons' lives easier and more independent. Interviews and co-creation workshops have been conducted with older persons and their carers in nine countries (Belgium, France, Germany, Italy, Poland, Slovenia, Spain, Turkey, and the UK) in order to co-design these technologies – i.e. a smart sofa, garment and shoes. The project's findings emphasise a strong need to feel independent, yet safe in older adulthood. MATUROLIFE concluded in 2021 with the launch of footwear, clothing and furniture prototypes equipped with electronics and sensors, whilst functional in terms of quality, safety and reliability.



<http://togethereupproject.eu/>



<http://maturolife.eu>

Our Research Work

Carers as partners in care

Integrating care, services and supporting activities means that the design and delivery of care is made in a more effective manner, so that users receive a continuum of preventive, curative, rehabilitative, and support interventions throughout the life course and in accordance with their actual needs over time. The interventions should be seamlessly applied across levels and areas of health and social systems. Carers are central to the planning, shaping and delivery of services for the people with care needs and in relation to support for themselves. When treated by other actors (i.e. care professionals) as equal partners in the delivery of care, informal carers enable people long-term care needs to remain at home and in their own communities safely, independently, with dignity and for longer. Eurocarers is therefore involved in various projects aiming to inform the design and implementation of integrated care.



ESCAPE (Evaluation of an integrated patient-centred biopsychosocial and behavioral collaborative CARE Pathway for the management of multi-morbid aged patients) is a 5 year-long project funded through the Horizon 2020 programme. ESCAPE builds on a combination of Wagner's chronic care concept and the collaborative care tradition in a model of blended collaborative care (BCC), using proactive communication with patients and health care providers in order to simultaneously support patients and care providers in a sustainable effort to tackle multiple physical and mental health problems. The project aims to extend the BCC framework for addressing the multiple medical and psychosocial needs of elderly multimorbid patients and their formal and informal carers in order to improve their QoL and medical disease outcomes.



<https://escape-project.org/>



The **ENhANCE** (European curriculum for family and community nurse) Erasmus+-funded Project seeks to address an existing skills mismatch in primary health care, by developing a European Curriculum designated to increase the specialization level of Family Community Nurses (FCN). Today, no European curriculum exists that details the knowledge, skills and competencies for nurses in this field. In 2021, ENhANCE In the context of the ENhANCE project, existing WHO frameworks defining core competencies of a family health nurse and in community nursing were used as a basis to develop and agree on the core competencies of the Family & Community Nurse (FCN). On that basis, the consortium produced the final version of the ENhANCE Family and Community Nurse (FCN) European Curriculum, which was accompanied by a toolkit to support the design local curricula.



<https://www.enhance-fcn.eu/>

Our Research Work

Giving Care – Empowering (In)formal caregivers by developing technical, soft and digital skills

The main objective of the Giving Care is to empower formal & informal carers as well as personal assistants & other health professionals by supporting their technical, soft & digital skills in order to respond to the gap in the Higher Education Institutions (HEIs) provision. This takes place via the design and implementation of an innovative Continuous Education Programme (CEP) and related materials/resources, based on independent modules. Giving Care seeks to offer a Guide for Personal Carers & Assistants as well as health professionals to enhance their professional development and their daily activities (e.g. Good Practices for Caring; How to take care of who cares; and selection of storytelling videos based on real cases with visual examples of care practices). Moreover, the project also aims to develop and promote a professional occupational profile for personal carers and assistants fostering their social & professional recognition, and providing them with the support & tools they need to take care of themselves & others.



InCare - Supporting INclusive development of community-based long-term CARE services through multi-stakeholder participatory approaches

InCARE aims to promote participatory, innovative and integrated approaches to long-term care policy and service development by focusing on aspects that are instrumental for system sustainability and innovation capacity: multi-stakeholder cooperation, evidence-based decision-making, capacity building and skills transfer. The project focuses on the development of a coherent and co-ordinated approach to the development of national care policies and services, with a focus on empowering local stakeholders, communities, care users and their families to contribute to and shape the development of LTC services.

InCare builds on the idea that social innovation in LTC should reflect the aspirations and needs of older people with functional or cognitive impairment and their carers, while emphasizing the role of local communities and service providers to shape care service delivery in innovative ways, facilitated by national policy-level support for adapting, adopting and enhancing these initiatives.



<https://incare.euro.centre.org/>

Our Research Work



Stay Safe - Preventing and responding to sexual violence against women with disabilities. The Stay Safe project aims to raise awareness and educate women with disabilities on how to respond to sexual harassment (both online and offline) and violent incidents, developing a training model which will apply the gender-based behavioural approach and will be based on creative drama techniques and gaming elements. Moreover, applying creative drama methodologies, it intends to train professionals working in the disability field on how to recognize the risks of sexual harassment to which women with mental disabilities are exposed to and how to support them.

The project, which concluded in 2021, carried out an analysis of the different forms of sexual harassment and sexual violence against women with disabilities that exist in participating countries (Italy, Greece, Spain, Portugal and Lithuania). Moreover, it produced a training manual targeted at social, health and GBV professionals and seeking to help them recognise and contrast sexual violence against women with disabilities; an online course for professionals working with women with psycho-social disabilities; a training programme for women with psycho-social disabilities; as well as various awareness-raising resources.



<https://staysafeproject.eu/>

Long-term care

The foundation of carer-friendly societies and of work-life balance for people with caring responsibilities is the prevention of frailty and dependency and the universal availability of high-quality professional long-term care services. These aspects are indeed essential to reduce the intensity of informal care provision and to allow carers to reconcile their caregiving with a demanding and fulfilling social and professional life. Investment in prevention and in care services should therefore be seen as a priority.

Consequently, Eurocarers is also involved in projects exploring models of care, which consider the needs and preferences of informal carers both as co-providers of care and as secondary users.



→ **Sustainable Care: connecting people and systems** (2017-2021): The Sustainable Care Research Programme is a multi-disciplinary ES-RC-funded programme (2017-2021), coordinated by Pr. Sue Yeandle's team at the University of Sheffield, which explored how care arrangements, currently 'in crisis' in parts of the UK, can be made sustainable and deliver wellbeing outcomes. The programme aimed to support policy and practice actors and scholars to conceptualise sustainability in care as an issue of rights, values, ethics and justice, as well as of resource distribution. The project's overarching objective was to advance understanding of sources of economic and social sustainability in care, especially how wellbeing outcomes can be achieved for care users, their families / carers and paid care workers.

Our Research Work

Sustainable Care was implemented along three research strands, namely:

- CARE SYSTEMS: Theorising the relationship between UK care systems and wellbeing;
- CARE WORK and RELATIONSHIPS: Wellbeing in care relationships, and the co-ordination and work of care; and
- Care, Sustainability and Wellbeing: A Conceptual and Analytical Framework for Policy and Practice in Care and Caring.



<http://circle.group.shef.ac.uk/sustainable-care/>



→ **FUTUREGEN** (Evolving gender differences in health & care across cohorts / Gender-ERA-Net, Austrian Science Fund, Swedish Research Council, Canadian Institutes of Health Research - 2019-2021) aims to understand how entwined GENDER inequalities in health and care-giving/receiving evolve across GENERations in connection with cultural and social contexts and individual realities, and how identified sex/gender inequalities may evolve in the FUTURE. Current gender inequalities in health and care can be attributed to present-day circumstances and to how people live their lives. Both are changing, but we know little about how these changes are shaping health and care and therefore cannot predict or ameliorate future sex/gender inequalities. To answer these questions, the FUTUREGEN team will apply novel quantitative methods to comparable international datasets covering Europe and North America and obtain older people's views through participatory qualitative research methods.



ENTWINE

INFORMAL CARE

→ **ENTWINE** (2018-2022) is a 4-year Marie Skłodowska-Curie Innovation Training Network (ITN), funded by the European Union, which aims to explore the drivers of carers' willingness to care; interventions, services and technology-based interventions to empower carers; as well as novel technology-based solutions to support informal care. ENTWINE has trained 15 Early-Stage Researchers (ESRs) as part of their PhD education.



<https://entwine-itn.eu/>



<https://futuregen.euro.centre.org/>

Who's who

The Eurocarers Executive Committee



President

**Sari
Tervonen**

Central
Association of
Carers in Finland



Vice President
Research

Henk Nies Vilans



Treasurer

**Anita
Vatland**

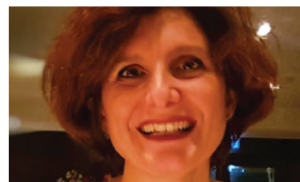
Norwegian alliance
for informal Carers



Executive
member

**Bruno
Alves**

Cuidadores
Portugal



Executive
member

**Sara
Santini**

National Institute
of Health and
Science on Ageing



Advisor to
the Board

**Sebastian
Fischer**

VOCAL – Voice of Carers
Across Lothian



Advisor to
the Board

**Elizabeth
Hanson**

Swedish National Family
Care Competence Centre



Advisor to
the Board

**Katherine
Wilson**

Carers UK



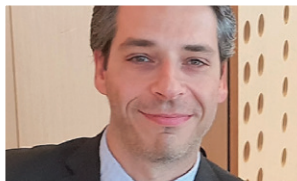
External
advisor

**Christine
Marking**

Marking Public Affairs

Who's who

The Eurocarers Secretariat



Executive Director

Stecy Yghemonos



Project Officer

Francesca Centola



Policy Officer

Claire Champeix



Senior
Communication
Officer

Olivier Jacqmain



Project Officer

Nadia Kamel



Administrative and
Financial Officer

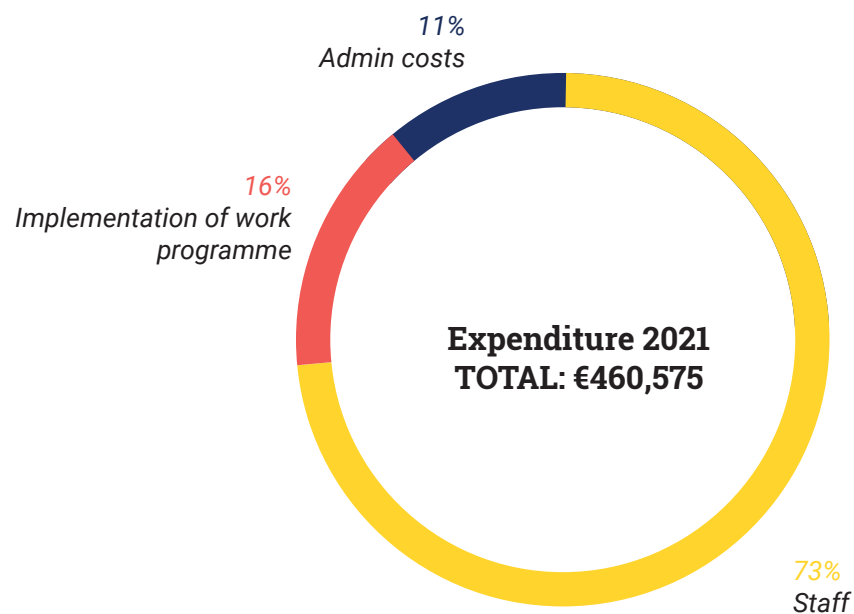
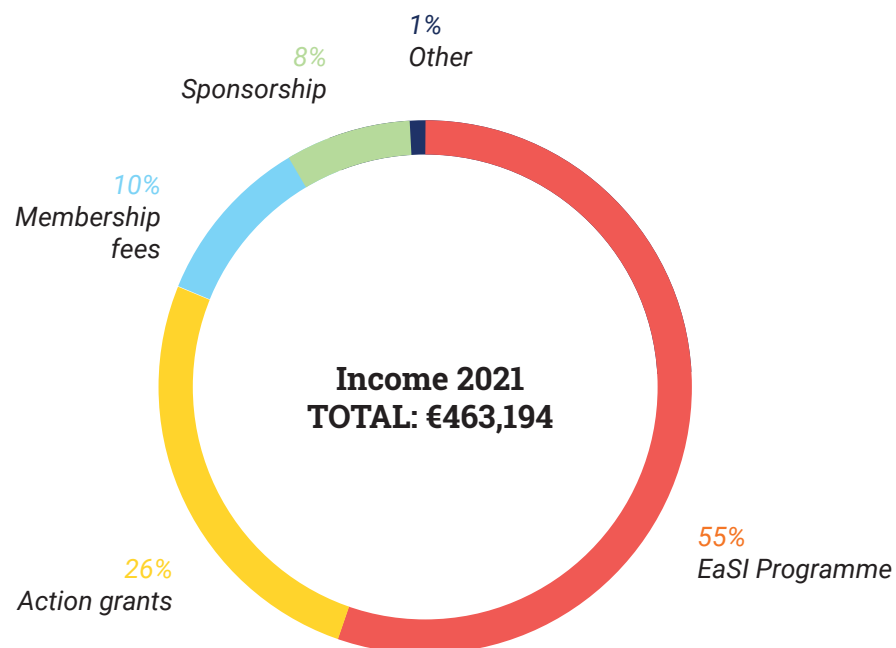
Riika Lempiäinen



Administrative and
Financial Officer

Jevgenija Nekrilova

How we are funded



Our members

Full members

European Centre for Social Welfare Policy and Research	Austria	Norwegian National Alliance for informal Carers	Norway
Institut Recherche Santé et Société, Université Catholique de Louvain	Belgium	Norwegian University for Science and Technology, Centre for Care Research	Norway
University College Ghent, Department of Education	Belgium	Cuidadores Portugal	Portugal
Magenta - KU Leuven	Belgium	ANCI - Panóplia de Heróis - Associação Nacional de Cuidadores Informais	Portugal
Diaconia of the Evangelical Church of Czech Brethren	Czech Republic	DGASPC-S1 General Directorate of Social Work and Child Protection, District 1	Romania
Carers Denmark	Denmark	University of Ljubljana. Faculty of Social Sciences	Slovenia
NGO Estonian Carers	Estonia	Anton Trstenjak Institute of gerontology and intergenerational relations	Slovenia
The Central Association of Carers in Finland	Finland	CEAFA: Confederacion Espanola de Familiares de Enfermos de Alzheimer y otras Dementias	Spain
Organisations for Carers Network Finland	Finland	The Swedish Family Care Competence Centre	Sweden
Association Française des aidants	France	Anhörigas Riksförbund (AHR), carers Sweden	Sweden
Federation Nationale des Aidants et Accueillants Familiales	France	Carers UK	UK
Centre for Quality in Care	Germany	CIRCLE (Centre for International Research on Care, Labour and Equalities), University of Sheffield	UK
wir pflegen e.V.	Germany	Carers Trust	UK
EPIONI	Greece	The Coalition of Carers in Scotland	UK- Scotland
Institute of Mental Health Semmelweis University	Hungary	VOCAL - Voice of Carers Across Lothian	UK- Scotland
Family Carers Ireland	Ireland		
Care Alliance Ireland	Ireland		
Istituto Nazionale di Riposo e Cura per Anziani (INRCA)	Italy		
Anziani e non solo società cooperativa	Italy		
SOS Malta - Solidarity Overseas Development Malta	Malta		
VILANS	Netherlands		
MOVISIE, Centre of Expertise for Informal Care	Netherlands		
VU University Amsterdam, Faculty of Social Sciences,	Netherlands		

Our members

Associate members

Austrian Carers Organisation	Austria
Samana	Belgium
Universiteit Antwerpen - Centre for Longevity Research (CELLO)	Belgium
Dr Sigrid Bosteels	Belgium
Aidants proches asbl	Belgium
Aidants proches Bruxelles	Belgium
Jeunes Aidants proches	Belgium
Alzheimer Bulgaria (Civil Association "Alzheimer-Bulgaria")	Bulgaria
DaneAge	Denmark
La compagnie des aidants	France
Proches Aidants France	France
AlliPa - Allianz pflegende Angehörige e.V.	Germany
GAT - Institute für Gesundheit, Görlitz	Germany
Athens Association of Alzheimer's Disease and Related Disorders	Greece
Greek Association of Alzheimer's Disease & Related Disorders	Greece
Associazione de Banfield (ONLUS ODV)	Italy
Associazione C'ENTRO	Italy
RBS Center fir Altersfroen asbl	Luxembourg
Community Development Institute	Macedonia
The Netherlands Institute for Social Research (SCP)	Netherlands
Mantelzorg NL, Dutch Association for Carers and Voluntary Help	Netherlands
SOCIA – Social Reform Foundation	Slovakia

Slovenian Federation of Pensioners' Organisations (ZDUS)	Slovenia
Grupo SSI - Grupo Servicios Sociales Integrados	Spain
Careum Stiftung	Switzerland
Pro Aidants	Switzerland

Observer Members

Myra Lewinter, University of Copenhagen Department of Sociology	Denmark
Tiina Autio	Finland
Dr. Henk Bakkerode	Netherlands
Marja Pijl	Netherlands
Dr. Jolanta Perek Bialas	Poland
Paulo Guilherme Mota Lourenço	Portugal
Simona Hvalic Touzery	Slovenia
Martha Mackay	Spain
Saul Becker	UK
Feylyn Lewis	UK
Daniel Phelps	UK
Dr Jitka Vseteckova	UK