

Consultation on the European Pillar of Social Rights

Fields marked with * are mandatory.

Welcome to the European Commission's online public consultation on the "European Pillar of Social Rights".

Are our social rights fit for the 21st century? The Pillar will identify a number of essential principles to address the challenges in the field of employment and social policies.

We want to involve everyone in shaping the European Pillar of Social Rights. We welcome contributions from citizens, social partners, organisations and public authorities, so have your say!

Please submit your contribution below until the end of 2016.

I. Questions for the identification of the respondent

*** Are you replying as an individual or as an organisation?**

- Individual
- Organisation

What is the type of your organisation?

- Business
- EU level organisation
- National level organisation

Your EU level organisation is a(n)

- NGO
- Trade Union
- Employers organisation
- Think tank/academia
- Other

*** Name of your organisation or institution:**

500 character(s) maximum

Eurocarers

*** Respondent's first name:**

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*** Respondent's surname:**

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*** Respondent's email address:**

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*** Postal address of your organisation or institution:**

500 character(s) maximum

3, rue Abbé Cuypers, 1040 Brussels - Belgium

Country

For individuals: country of residence.

For organisations: country where the organisation is based or country where the organisation's headquarters are.

Belgium

Register ID number (if you/your organisation is registered in the Transparency register):

If you would like to register, please refer to the following webpage to see how to proceed : <http://ec.europa.eu/transparencyregister/info/homePage.do>

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*** Your reply:**

- Can be published with your personal information** (I consent to publication of all information in my contribution and I declare that none of it is under copyright restrictions that prevent publication)
- Can be published in an anonymous way** (I consent to publication of all information in my contribution except my name/the name of my organisation and I declare that none of it is under copyright restrictions that prevent publication)
- Cannot be published - keep it confidential** (The contribution will not be published, but will be used internally within the Commission)

II. Questions for the consultation

The Commission invites all interested parties to reply to the questions set out in the questionnaire below, together with any additional comments, by 31 December 2016. (*See also [Commission communication "Launching a consultation on a European Pillar of Social Rights", COM\(2016\) 127 final](#)*)

On the social situation and EU social "acquis"

1. What do you see as most pressing employment and social priorities?

2000 character(s) maximum

- The social dimension of the EMU has been consistently underdeveloped. We welcome the Social Pillar as a much needed new step towards a more balanced EU. The Pillar has the potential to affect the life of numerous informal carers across the EU and these should therefore be involved in this debate.
- Informal care (1) is crucial in the provision of adequate care and should be supported accordingly. Supporting informal carers would not only help lift up barriers to employment and social inclusion, it would also be a sound investment for social cohesion and the future of care systems. There are more than 100 million carers in Europe today - a figure that is probably underestimated. Informal carers currently provide over 80% of all care and the economic value of unpaid care - as a percentage of the overall cost of formal long-term care ranges from 50 % to 90 % . Informal care is one of the cornerstones of our care systems and a key asset to address the challenges posed by demographic ageing. Informal care can be seen as a practical measure to contain the costs of services while also seconding supporting widespread preferences among the elderly for being cared for in their own home.
- The significant contribution of informal carers to society has a cost. Being a carer is often associated with poverty, physical and mental health problems, isolation, work/care balance issues and financial worries. The predominance of women in informal care exacerbates the gender pay and pension gaps. The prevalence of people from disadvantaged groups exacerbates inequalities. More and more people are likely to provide informal care during their working life as well as when older and retired. Without adequate support, these people are likely to reach a breaking point and will not be able to provide quality care.
(1) providing care (usually unpaid) to someone with a chronic illness, disability or other long-lasting health or care need, outside of a professional or formal framework.

2. How can we account for different employment and social situations across Europe?

2000 character(s) maximum

- The recognition of the role and contribution of informal carers is very uneven across the EU. Depending on the type of long-term care system in place, which can be more or less oriented towards formal care, and reliant on social insurance against long-term care risk, there are significant variations of support provided to informal carers. Overall, carers' organisations across the EU highlight the lack of support to carers, as well as a huge discrepancy between regions and municipalities.
- Despite their diversity, long-term care systems face the same four main challenges - i.e. a growing demand, a declining supply of carers, a quality challenge and a financing challenge. A growing number of policies and programmes initiated by public authorities seem to take into consideration informal carers as part of a response to these challenges. However, to date, the combined impact of the financial and economic crisis and austerities policies and the lack of coordinated approaches have been detrimental to the development of much-needed supportive approaches and services.
- Research suggests that little is known about the availability of support to carers in Europe and there is an obvious lack of available comparable data and comparative analysis in the area. An exhaustive overview of 'Informal care at the European level' was produced in 2010 as part of the EU-funded INTERLINKS project, which has nevertheless not been updated since, even though many developments have occurred in the last years, notably with regards to the perception of carers' role, as well as the policy, legislation and good practices that concern them.

3. Is the EU "acquis" up to date and do you see scope for further EU action?

2000 character(s) maximum

- Informal carers are not sufficiently recognised in the current EU "acquis". Yet, in recent years, the crucial role they play has been increasingly acknowledged by EU Institutions, notably through:
 - The European Innovation Partnership on Active and Healthy Ageing (2011), which includes carers' organisations;
 - The EC Staff Working Document (SWD) on exploiting the employment potential of the personal and household services (2012);
 - The EC SWD "Long -Term Care in ageing societies - Challenges and policy options" (2013) accompanying the Social Investment Package;
 - The joint EC-SPC report "Adequate social protection for long-term care needs in an ageing society" (2014).
 - The consultation on "Possible action to address the challenges of work-life balance faced by working parents and caregivers" (2016);
 - The own-initiative report highlighting the lack of recognition faced by domestic workers and carers in the EU from the European Parliament (April 2016).

- Consequently, the Social Pillar should seek to further support the development of a 'carer-friendly society' that promotes increased social capital by enabling informal carers to achieve a stable work/life balance and access appropriate health, education, and adequate income while offering good, informed quality care and preventing neglect and abuse. Such a transformation should build on increased awareness, intergenerational solidarity, preventive education, as well as adequate income, work-life balance policies, and access to equitable quality services.

- The impact of informal caregiving can be felt in many settings and across the life course. A comprehensive and multidimensional EU initiative on carers should be developed. Support to carers should be mainstreamed in all relevant EU policies, and the principle of a 'care proof-check' adopted. In parallel, opportunities to take stock and evaluate achievements related to carers' support should be created to pave the way for further progress.

On the future of work and welfare systems

4. What trends would you see as most transformative? [Please select at most three from the list below]

between 1 and 3 choices

- Demographic trends (e.g. ageing, migration)
- Changes in family structures
- New skills requirements
- Technological change
- Increasing global competition
- Participation of women in the labour market
- New ways of work
- Inequalities
- Other

5. What would be the main risks and opportunities linked to such trends?

2000 character(s) maximum

- The ageing of our societies puts at stake our capacity to ensure quality and affordable long-term care to all frail and dependent people. The risks are manifold:

- A shortage of available carers;
- Increased health-related difficulties among informal carers who will have to give care when they get older themselves;
- A rise in age-related chronic illness;
- Increasing need for long-term care coupled with a lack of available resources to finance it;
- Growing inequalities and exclusion.

On the other hand, this is the opportunity to facilitate a paradigm shift in the way health care and long-term care are organised, to change representations attached to caring and to move towards a carer-friendly society.

- Changes in family structures contribute to minimise the possibilities of informal caregiving. Professional mobility, migration and cultural changes also affect countries where long-term care systems are based on informal carers' efforts. Yet, if properly addressed, these changes give an opportunity to develop integrated approaches provided that adequate support is granted to informal carers. This can contribute to ensuring that quality informal care is provided under favourable conditions by people who have made the choice to do so.

- Technological progress allows for innovative solutions to be developed in order to facilitate the delivery of community-based long-term care and the provision of support to informal carers (e.g. electronic networks supporting information, counselling, medical advice and training online, assisted ambient living, support to people with functional limitations, support to care coordination ...). Opportunities are huge, provided that innovation is properly assessed, supported and disseminated so that it is accessible to all, ethical issues are adequately addressed, both recipient and carers are involved in relevant research and development.

6. Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references?

2000 character(s) maximum

In Ireland, the National Carers Strategy has been useful as a building block for new developments and to set out national goals. The ability to highlight failures and successes by Government in addressing the needs of informal carers is positive. The Carer's Leave Act allows employees to take 13-14 weeks off to care for a family member. Leave is unpaid but the employee's job is protected for the duration of the leave.

In Estonia, a Task Force has been set up in cooperation with the government's office and the Ministry of Social Affairs for the period 2015-2019, with the aim to reduce the burden of care, with the support of the NGO Estonian Carers. It will design policy proposals for a national long-term care system.

In Italy, the region Emilia Romagna approved a Regional Law (L.R.2/14) for the recognition and support of informal carers in March 2014. Caregivers are recognised by law as an informal element and a resource of an integrated care system, where all the actors are actively involved, with a clear definition of their roles and a coordination (ensured by the case manager). The law envisages different measures to support caregivers. This law is the result of a process of active citizenship.

In the UK, 'Employers for Carers' aims to ensure that employers have the support to retain employees with caring responsibilities. It provides tailored-made information, practical advice, training and consultancy for small and large business seeking to develop carer friendly policy and practice. Services offered by Employers for Carers build on the expertise of 'Carers UK'.

In Sweden, ACTION is an integrated support provided by Borås municipality to frail older people and their carers. It provides a range of web-based educational caring programmes for carers of older people together with videophone facilities to enable direct peer support with other users and access to a call centre run by professionals, together with an in-depth computer training course.

On the European Pillar of Social Rights

7. Do you agree with the approach outlined here for the establishment of a European Pillar of Social Rights?

- I strongly agree
- I agree
- I disagree
- I strongly disagree

Please specify:

2000 character(s) maximum

Eurocarers very much welcomes the launch of a consultation on a European Pillar of Social Rights, aimed to rebalance the process of integration within the European Monetary Union through a stronger focus on employment and the social dimension.

We agree that a series of challenges faced by our societies must be addressed through a rights-based approach, and we are convinced that the EU dimension can provide added value in these domains, building on social acquis.

As the organisation working for informal carers across the EU, we welcome the recognition by the EC of the difficulties encountered by informal carers to access and retain employment, and the proposal that “people with caring responsibilities”, as well as parents, should benefit from “adequate leave arrangements” and “access to care services”.

However, we believe that a more ambitious approach should be adopted aimed at moving towards a much needed carer friendly society, likely to ensure:

- The effective implementation of informal carers rights - which are undermined to date;
- The sustainability of our health and long-term care systems.

Evidence shows that support to informal carers makes a positive difference for the society as a whole in a variety of areas, ranging from health and long-term care provision to gender equality, equal opportunities, employment, pension, minimum income, education... Reciprocally, any policy developed in these areas has a potential impact on informal caregiving.

Our detailed comments below show how the issue of informal caregiving is interrelated with major challenges, and why supporting informal carers together with ensuring access to services is a sound investment for the future of our ageing societies in the context of tightened public budgets.

8. Do you agree with the scope of the Pillar, domains and principles proposed here? (If you wish to provide detailed comments on any of the 20 domains, please see the section "Detailed comments by domain" below)

| | I strongly agree | I agree | I disagree | I strongly disagree |
|---|----------------------------------|----------------------------------|-----------------------|-----------------------|
| 1. Skills, education and life-long learning | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 2. Flexible and secure labour contracts | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| | | | | |
|--|----------------------------------|----------------------------------|-----------------------|-----------------------|
| 3. Secure professional transitions | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 4. Active support for employment | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 5. Gender equality and work-life balance | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 6. Equal opportunities | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 7. Conditions of employment | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 8. Wages | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 9. Health and safety at work | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 10. Social dialogue and involvement of workers | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 11. Integrated social benefits and services | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 12. Health care and sickness benefits | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 13. Pensions | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 14. Unemployment benefits | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 15. Minimum income | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 16. Disability benefits | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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|----------------------------------|----------------------------------|----------------------------------|-----------------------|-----------------------|
| 17. Long-term care | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. Childcare | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. Housing | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. Access to essential services | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Are there aspects which are not adequately expressed or covered so far?

2000 character(s) maximum

- Informal carers face discrimination. We welcome their recognition under the areas 'gender equality and work life balance' and 'pensions', however they should be granted support for accessing their rights in all areas, including education, housing, essential services... Support to carers should be envisaged not only in relation to their access to employment, but also on a rights-based approach and on the basis of their increasingly important role in the provision of (long-term) care.
- Informal care should be supported as a possible choice and an essential element of integrated community-based care services. This requires partnerships between all care providers designed around patient needs. Adequate and quality home care is a crucial element of the shift from institutional to community-based care, as supported by EU institutions and preferred by a majority of dependent people. Besides, stepping out of employment for a given period of time in order to take care of a loved one can also be a positive and gratifying experience for carers. This option should therefore be recognised and supported as part of a sustainable long-term care system, in parallel with other residential alternatives. Informal carers and care professionals need to coordinate, which requires flexibility from the professional care sector. This vision builds on the World Health Organisation (WHO) approach where patients are seen in the context of their family and care network.
- We welcome the attention given to healthcare, social services and long-term care, however:
 - An integrated approach should be applied to health services in line with the European Framework for Action on Integrated Services Delivery defined by the WHO;
 - Social services should be part of an integrated approach together with health care and long-term care services;
 - Services supporting carers should be considered as essential services;
 - The UNCRPD ratified by the EU in 2010, should be used as a reference.

9. What domains and principles would be most important as part of a renewed convergence for the euro area? (Please select maximum 5)

between 1 and 5 choices

- 1. Skills, education and life-long learning
- 2. Flexible and secure labour contracts
- 3. Secure professional transitions
- 4. Active support for employment
- 5. Gender equality and work-life balance
- 6. Equal opportunities
- 7. Conditions of employment
- 8. Wages
- 9. Health and safety at work
- 10. Social dialogue and involvement of workers
- 11. Integrated social benefits and services
- 12. Health care and sickness benefits
- 13. Pensions
- 14. Unemployment benefits
- 15. Minimum income
- 16. Disability benefits
- 17. Long-term care
- 18. Childcare
- 19. Housing
- 20. Access to essential services

Comments:

2000 character(s) maximum

Skills, education and life-long learning, gender equality and work-life balance, health and safety at work, pensions and long-term care are key areas where the EU needs to define a more robust response to successfully cope with the ageing challenge.

Uncoordinated policies aimed at developing an equal level playing field in these areas would be damageable to the EU and would generate risks of:

- Increasing economic divergence within the EU;
- Missing the opportunities offered by the silver economy at European level;
- Missing the opportunity to create new formal jobs, as well as foster the development of undeclared care work;
- Exacerbate the imbalance of available carers between countries, with those where the care sector is more developed attracting migrant workers, and others facing a shortage of care workers.
- On the contrary a coordinated action would allow to share experience and knowledge, develop research and avoid a race to the bottom.

10. How should these be expressed and made operational? In particular, do you see the scope and added value of minimum standards or reference benchmarks in certain areas and if so, which ones?

2000 character(s) maximum

The secondary law should systematically recognise informal carers and provide them with adequate protection in all relevant policy areas.

Policy coordination engaged within the Europe 2020 Strategy should include objectives and quantified targets, regarding:

- The provision of accessible, affordable and adequate health long-term care services, in residential services and home-base;
- Coordination of relevant social, health and long-term care services putting the patient and the informal carer at the centre;
- Support services for informal carers;
- Specific support for young carers;
- Training for informal carers.

Standards and benchmarking instruments would help build consensus, and assess progress. To avoid downward convergence, they should build on improved comparative research and collection of data, and they should be co-designed with carers.

The use of all EU funding possibilities (ESF, ERDF, ESIF) should be aligned with these objectives. Support to informal carers must be integrated in the objectives for the next programming period. Corresponding budgets should not be considered as an expense but as an investment.

As part of the activities directly supported by the EU, the European Commission should:

- Develop awareness raising initiatives (a European Year of Carers for example);
- Encourage the exchange of expertise and experience through EU action programmes and projects;
- Keep supporting organisations that represent carers at EU level and are active in transnational exchanges and awareness raising activities (for ex. through the EaSi programme).

Care-related issues are often overlooked as they fit at the intersection between a range of policies areas. Governance should be adapted to address them better. Notably by:

- Ensuring closer cooperation on informal care between relevant Council preparatory bodies, and between the relevant Directorate-Generals.
- Involve carers in all relevant consultations and advisory boards

Detailed comments by domain

If you wish to provide detailed comments on any of the domains, please select one or more from the list below and fill the table(s) and comment box(es) underneath. (A detailed description of the domains and principles is available in the [Annex "A European Pillar of Social Rights - Preliminary Outline"](#) to the [Commission communication "Launching a consultation on a European Pillar of Social Rights", COM\(2016\) 127 final](#)).

- 1. Skills, education and life-long learning
- 2. Flexible and secure labour contracts
- 3. Secure professional transitions
- 4. Active support for employment
- 5. Gender equality and work-life balance
- 6. Equal opportunities
- 7. Conditions of employment
- 8. Wages
- 9. Health and safety at work
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- 12. Health care and sickness benefits
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- 15. Minimum income
- 16. Disability benefits
- 17. Long-term care
- 18. Childcare
- 19. Housing
- 20. Access to essential services

1. Skills, education and life-long learning

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|----------------------------------|----------------------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

- We believe that basic knowledge about caregiving issues, existing sources of information and support should be part of the ‘basic skills and key competences’ to be acquired by all.
- Relevant training is essential to support informal carers who have to face complex diseases and manage multiple treatments, while maintaining their own condition. Quality and accessible training should be made available to all.
- Accessing training is extremely difficult for carers due to their caregiving responsibilities. Respite care should be made available to all carers as part of support measures.
- In addition, the valuable skills acquired by carers on the job should be recognised and validated. Indeed, informal carers develop both specific skills (symptom management, daily care...) and transversal skills (communication, coordination...). The recognition and validation of these skills is an important asset to overcome barriers in returning to work after a caring period.
- Informal caregiving during youth is an important source of low attainment at school and early school leaving. Awareness about the challenges related to informal caregiving during youth should be raised within schools and universities, among students, teachers and management. An effective, equitable and responsive education system offer young carers understanding and personalised support to allow them to fully achieve their potential.
- The EU can be instrumental in:
 - Developing comparative research and exchange of good practices in relation to training and certification for informal carers;
 - Encouraging the transnational recognition of skills acquired through caregiving experience;
 - Supporting projects focusing on training and reintegration needs of carers as they transition from an active caring life to life post caring.
 - Facilitating the development of a common framework for the recognition and certification of caring skills accessible to informal carers.

2. Flexible and secure labour contracts

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, we believe it is important that flexible and secure working contracts are organised around the needs of informal carers. Indeed:

- In order to be able to retain employment, working informal carers should be entitled to flexible working conditions - including flexible working hours, care leaves, part-time work, allowing them to combine work and care responsibilities. It is necessary for informal carers to be able to obtain such flexibility at short notice when needed.
- Working carers should not lose income security, pension and social security rights when reducing or interrupting their paid work as a result of their caregiving activities. Compensations should be guaranteed.
- Working carers should not lose the possibility to return to full-time work after opting for part-time work for a given period.

3. Secure professional transitions

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, we suggest the following points as regards informal carers:

- After a long interruption due to caregiving activities, informal carers are in a particularly difficult position to re-enter the labour market and they should be specifically supported.
- Since informal carers do, through their caregiving activities, acquire a number of valuable skills (both specific and transversal), formal recognition of these skills acquired through experience can be a positive asset (see also point comments on 1. Skills, education and lifelong learning)
- Informal carers' entitlement to flexible employment should be legally established; so that it is not left at the discretion of individual enterprises and does not hinder carers' professional mobility.

4. Active support for employment

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, we consider important that informal carers are considered as a group at risk by employment policies. Active labour market policies targeting young people and long term unemployed people, should take into account the specific constraints and needs of informal carers, offer tailor-made support and services, and depart from any punitive approach.

5. Gender equality and work-life balance

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|----------------------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Eurocarers welcomes the recognition that “people with caring responsibilities”, as well as parents, should benefit from “adequate leave arrangements” and “access to care services”. This approach can only be beneficial to women, who provide most of the informal care, especially when intensive care is needed, with a detrimental impact on their participation in the labour market and their social inclusion. Indeed, they should be strongly supported to remain or to get back to the labour market, through adequate leave arrangement and access to quality and affordable care services. Additionally, we recommend the following regarding gender equality:

- A more gender equal sharing of care: men should be encouraged and adequately supported to take on caregiving responsibilities.
- The impact of caregiving on the gender pay and pension gaps should be better analysed, as well as the discrimination faced by female carers at work. Awareness raising and support should be encouraged in companies.
- Adequate leave arrangement and access to care services should be part of a holistic supportive policy including also formal recognition, easy access to information, guidance, advice and training, emotional support as well as financial security. Such support should be provided across the life cycle.
- Informal carers should be supported independently from their choice to remain on the labour market or to devote themselves to their caregiving responsibilities.

6. Equal opportunities

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, we want to highlight the following :

- Informal carers often face discrimination in the workplace, as well as at school or at the university. Such discrimination should be combated through awareness raising activities highlighting the contribution made by carers, as well as the specific difficulties they are facing.
- A number of third country nationals and ethnic minorities are employed - some of them illegally - in caregiving activities, with poor working conditions. Recognising, developing and validating their caring skills could help improve their status on the labour market, given the pressing need for quality long-term care services. Beyond the implementation of these workers' rights, this will also contribute to enhancing care, and to countering the negative representation associated with caring, which affects these workers and informal carers.

7. Conditions of employment

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, it is important to underline that:

- As part of the development of quality long-term care services, all workers in the care sector should be entitled to information and protection against unjustified dismissal. The same rights should apply to privately-hired in-house care workers. (This concerns also the issues of wage and health and safety at work).
- Informal carers, under some national or regional arrangements, may receive direct or indirect payments in the form of social benefits. They should be entitled to workers' rights.

9. Health and safety at work

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, from the point of view of informal carers, it is important to underline that:

- Informal care has a huge impact on the physical and mental health and well-being of carers themselves;
- Maintaining one's own health while caring can be extremely challenging, especially for older carers, working carers... Carers' exhaustion and health difficulties often mean huge personal, societal and economic costs. Indeed, this can lead to the hospitalisation or institutionalisation of the caree or, when carers keep caring, to their exclusion from the labour market, and the reduction of the number of healthy life years they can expect.
- For these reasons, health promotion and prevention for carers should be ensured in health services (e.g. need for a systematic health and social assessment of carers and of their care burden).
- Working carers' health and well-being should be promoted in the workplace,
- Supporting carers' health and well-being can also be achieved through better housing support, access to equipment and appliances, access to assisted ambient living technologies...
- Access to respite care for all carers is a key factor enabling carers to take care of their own health.
- As part of the development of quality integrated care services, health and safety at work should be guaranteed to all workers in the care sector, including privately-hired in-house care workers.

10. Social dialogue and involvement of workers

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, from our point of view, it is important to underline that innovative policies and practices increasingly build on the recognition of the expertise of informal carers, as a way to ensure the relevance, the efficiency and the ownership of the solutions envisaged.

- Informal carers together with the people they care for, should be consulted in the design, delivery and evaluation of policies related to disability, health and long-term care.
- They should also be involved in the design of innovative technologies and practices aimed at facilitating caregiving.
- Carers' organisations empowering them and voicing their concerns and recommendations should be supported at all levels.

11. Integrated social benefits and services

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC proposal in this matter, from our point of view, it is important to underline the following:

- In order to address the growing challenges of the protection of ageing and disadvantaged population in the EU, alignment should also include health and long-term care services, together with relevant services and social benefits. (See comments on principles 12 and 17)
- Putting users at the core, improving their situation, building on their empowerment and participation, should be the main objectives of the integration of services and benefits.
- Differences in the provision of long-term care between EU members are more pronounced than in any other field of social protection. Ensuring adequate, accessible and affordable long-term care for all EU citizens calls for greater positive convergence in the coming years.

12. Health care and sickness benefits

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC'S proposal in this matter, we want that healthcare and sickness benefits can play a key role in supporting informal carers.

- Given the potentially detrimental impact of caregiving on the (physical and mental) health of carers, health promotion and prevention strategies should be specifically developed to target carers.
- Specific measures should be taken to allow informal carers to access timely quality and affordable health care. Indeed, they - more than others - are confronted to obstacles related to costs and accessibility.
- For carers whose health is undermined by the burden of caregiving, sickness benefits are part of their crucial financial security. They should be entitled to adequate sickness benefits in accordance with their real needs.

Integrated social, health and long-term care services

The lack of care coordination between primary, community, hospital, specialty care, social care and the patient is detrimental to care quality, to care efficiency, and to patient safety. Informal carers play an important preventative role in the development of certain diseases, and in the delay of admission in hospital and long-term institutional care. They should be supported in this role and be given a central role in integrated health and long-term care services. (See also comments in principles 11 and 17).

13. Pensions

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC'S proposal in this matter, we want to highlight the following :

- Eurocarers welcomes the principle that "care periods" should be adequately credited in order to address the gender pension gap. Both caring for children and for family, relatives or friends should be considered.
- Action should also be taken to address the consequences of caregiving on the associated gender pay and pension gaps (see comments on principle 5).

14. Unemployment benefits

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Though it does not fall into Eurocarers' area of expertise to assess the EC's proposal in this matter, we warn about the situation of informal carers, who face major difficulties when trying to retain employment or return to the labour market. Informal carers face discrimination on the labour market, they lack supportive services likely to help them combine work and care, as well as adequate flexibility in employment. For them, the definition of 'adequate unemployment benefits' and 'sufficient time' should be based on their particular needs. Pushing towards any kind of employment irrespectively of this reality would only undermine our long-term care system, and aggravate poverty in this category of the population.

- Any activation policy should take due account of the specific constraints attached to informal caregiving, and ensure personalised support to unemployed informal carer.
- The participation of informal caregivers in employment will only be sustainable provided that they get personalised support building on available, accessible and affordable services, adequate income and carer-friendly employment regulation.

15. Minimum income

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|----------------------------------|----------------------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

Informal carers are more likely to experience poverty and social exclusion than the general population. Taking on caregiving responsibilities often results in long-term financial hardship as the loss of income from employment is often compounded with higher housing, utility and transportation costs linked to caring (medicines, aids, home modifications, health care and specialised transport). Available income supports are not always well known and taken-up by informal carers. Besides, they remain globally insufficient to ensure an adequate standard of living and social inclusion for informal carers. In addition to the guarantee of an adequate minimum income accessible to all, combating poverty among informal carers requires the following:

- Adequate minimum income schemes should take into account in a personalised way the out-of-pocket expenditure and extra housing costs linked to dependency, which are often born partly or totally by informal carers.
- While informal carers should be supported in their endeavour to return to the labour market, they should be given the right to choose their priorities between care and work, without being condemned to poverty when prioritising care.

16. Disability benefits

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|----------------------------------|----------------------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

- Eurocarers welcomes the attention given to the need to ensure a decent standard of living to people with a disability. According to the United Nations Convention on the Rights of Persons with Disabilities, an “adequate standard of living should be guaranteed for persons with disabilities and their families”. It is indeed crucial for the well-being and social inclusion of the person with a disability as well as for the sustainability of home-based long-term care provided by relatives that both the persons with a disability and informal carers are supported through adequate services and income.

- The Social Pillar should also be instrumental in implementing the right to live in the community (as stated in the Article 19 of the United Nations Convention on the Rights of Persons with a Disability), notably through empowering and supporting informal carers.

17. Long-term care

| | I strongly agree | I agree | I disagree | I strongly disagree |
|--|----------------------------------|----------------------------------|-----------------------|-----------------------|
| Do you agree with the challenges described? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Is the principle addressing those challenges in the right way? | <input type="radio"/> | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Should the EU act to put in reality this principle? | <input checked="" type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have other comments or additional suggestions? For instance: how to address these challenges in the right way? How should the EU act to put in reality this principle?

2000 character(s) maximum

'Integrated care' and 'support to informal carers' should underpin this principle.

Integrated care

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

- Build on the Social Protection Committee's initiative on a Voluntary European Quality Framework on social services (2009) as well as on the European Quality Framework for long-term care services (WeDo project);
- Facilitate the conciliation between work and caring;
- Be personalised, and coordinated around the needs of the patient and the informal carers;
- Build on the recognition and the empowerment of informal carers;
- Underpin the provision of adequate health and long-term care both at home, in parallel with the development of deinstitutionalisation policies, and in care institutions and hospital;
- Address the lack of take up of existing supports through awareness raising initiatives, and reach out informal carers;
- Develop adequate training targeted at professional and informal carers, focusing on the delivery of quality integrated care;
- Involve all the relevant stakeholders, including public and private health providers, local and regional authorities...

Supporting informal carers

Supporting informal carers is key for the needed evolution from an institutional to a community-based model of care . Any policy dealing with long-term care should build on patients and their (informal) carers' needs and be designed in cooperation with them.

Contact

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