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Future EU care policy faces major social challenges

Proposals for strengthening informal care

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Europe's population is getting older. That is just one of the reasons why European care systems will come under dramatic pressure in the coming years and are facing major socio-political challenges and financing problems. The backbone of the entire system is so-called informal care - i.e. care provided by relatives or friends in the home environment. It accounts for over 80% of care across Europe. If fewer wage earners are available to care for an increased number of people in need of long-term care, this will have repercussions for household finances as well as the way in which households use their income and time. Care policy is of great economic importance and will have a profound impact on the everyday lives of many people.

The EU now wants to renew its care policy. On 7 September, the Commission will therefore announce a comprehensive EU care strategy. The EU faces a dilemma here because basically care is a matter for the Member States. This is also appropriate due to the varying, country-specific preferences. The Commission must respect the purview of the Member States and still propose measures capable of substantially supporting care systems. cep has identified impulses for a future EU care policy and proposes the following measures to strengthen informal care:

- Support services: EU citizens are often unaware of the available (financial) support from Member States, so benefits are not claimed. In this respect, there is a need for information which should be met at EU level by corresponding multilingual information portals.
- Work-life balance: The COVID 19 pandemic has changed the working world. The Directive on Work-Life Balance for Parents and Carers [(EU) 2019/1158] should be further developed to allow for more flexible employment and working time models where there are caring responsibilities.
- Uniform definitions and policy evaluation: Member States should agree in the Council on a common definition of informal care, which can be adopted in the form of a non-binding recommendation. This respects the purview of the Member States whilst also allowing measurable targets to be agreed at EU level. At the same time, special attention should be given to supporting family carers and promoting their return to the labour market.

Best Practice: Member States should be able to learn from pioneers in the field of care. The EU therefore needs to promote the exchange of ideas between Member States and with third countries. This will allow best practices can be exchanged and implemented across the EU. The EU can and should provide supportive resources in this regard, e.g. for the development of information and learning platforms.

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1 Introduction

Especially in an ageing society, the provision of care is a challenge for society as a whole and involves a variety of social, labour market and financial policy dimensions. A person in need of care in the EU will have to be cared for by an even smaller number of people in the future due to demographic and social changes. This increases the probability that each individual will have to become a carer.¹

The COVID 19 pandemic has also revealed the need to strengthen European care systems.² Thus, nursing staff have been and still are confronted with enormous workloads and personnel shortages. This not only applies to the situation in hospitals but also to care of the elderly and home care. Carers, people in need of care and their relatives are suffering in equal measure from this situation.

There is acute need for action throughout the EU, most notably due to the ageing European population,³ coupled with skills shortages in the care system⁴ and a financing base under strain⁵. Member States are faced with the immense task of organising needs-based yet humane care, with scarce resources. A European care strategy that supports more resilient and sustainable care systems in the Member States is therefore more important than ever in terms of social policy.

The EU Commission intends to adopt - probably on 7 September - a comprehensive European strategy for care and support.⁶ In the accompanying Communication, it will focus on how to improve the availability, accessibility, affordability and quality of care and support services.⁷

Care systems, however, are designed at national level. This is also appropriate in view of the varying, country-specific preferences. The EU Commission must respect the national competence of the Member States and still propose measures that can substantially support care systems and, in the best case, help to make them more resilient.⁸

In principle, care can be provided by (specialised) staff in hospitals, retirement homes, rehabilitation facilities or in the outpatient (home) environment ["formal" care],⁹ but also of course "informally", i.e. by relatives or friends.¹⁰ The latter is of immense importance for various reasons: While about 6.3 million people in the Member States (EU-27) were engaged in providing formal long-term care in 2019, 44 million people regularly - i.e. more than twice a week - were engaged in providing informal care activities for family members, neighbours or friends.¹¹ Thus, informal carers account for over 80% of

¹ See UNECE (2019), <u>The challenging roles of informal carers</u>, p. 5. All sources last accessed on: 30 August 2022

² See European Commission / Social Protection Committee (2021), Long-term care report. Trends, challenges and opportunities in an ageing society, p. 12.

³ See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change</u>, p. 10.

⁴ In the period 2018 to 2030 alone, 11 million newly trained health and care professionals, or professionals from other countries, will be needed in the EU-27. See Grubanov Boskovic et al. (2021), <u>Healthcare and long-term care force</u>. <u>Demographic challenges and the potential contribution of migration and digital economy</u>, p. 17.

⁵ Some European countries have recognised the need for sustainable financing of care systems and have initiated reforms. See for example Kraus et al. (2020), <u>Pflegesysteme im internationalen Vergleich</u>, in: Jacobs et al. (Eds.), Pflege-Report 2020, p. 36.

⁶ See European Commission (2021), <u>Commission Work Programme 2022</u>, p. 3. A consultation has already been carried out in advance, the results of which are available <u>here</u>. See also the <u>"Call for evidence for an initiative"</u>, <u>Ares(2022)1514879</u> hereinafter "Commission document".

⁷ Commission document, p. 3.

⁸ See Commission Proposal, p. 3.

⁹ See Eurofound (2020a), <u>Long-term care workforce: Employment and working conditions</u>, p. 3.

¹⁰ Ibid.

¹¹ Ibid., p. 7.

care across Europe.¹² These figures underline that the vast majority of care in Europe has so far been informal.¹³

This cep**Input** aims to provide impulses for a future European care policy in relation to the so-called informal¹⁴ long-term care of older people, in particular in order to improve the situation for informal carers and informal care as a whole. These concern (1) work-life balance for families and carers, (2) common definitions and targets, and (3) learning from pioneers.

2 Fundamentals

2.1 Demographic and social change

General trend

Demographic forecasts leave no doubt that a significant ageing of the European population is taking place.¹⁵ This is due to higher life expectancy¹⁶ and fewer births.¹⁷ For example, the number of people in the EU aged 65 and over is projected to increase from 92.1 million in 2020 to 130.2 million in 2050.¹⁸ At the same time, the birth rate in the EU-27 averaged 1.5 children per woman in 2020.¹⁹ This falls considerably short of a birth rate of 2.1 children per woman²⁰, which is necessary to maintain the population at a constant level.²¹ This will not only result in an overall European society that is shrinking (also with regard to people of working age²²), but also in one that is increasingly composed of older people.²³ Statistically, this goes hand in hand with an increased risk of medical costs and the need for long-term care.²⁴ Due to demographic change, a substantial increase in cases requiring long-term care is also forecast. One example is Germany, where - depending on the development of life expectancy - the number of people in need of long-term care will see a huge increase. While 4.6 million people were

¹² See Eurocarers (2018), Enabling carers to care - An EU Strategy to support and empower informal carers.

¹³ In addition, in the event that care is needed, there is a strong preference - and probably not only in Germany - to be cared for at home; see Federal Ministry of Education and Research (2017), <u>Wie möchten die Deutschen im Alter gepflegt</u> <u>werden? - An interview</u>. Ideally, there should be freedom of individual choice between informal and formal care. Resilient care systems should in principle make both possible by way of the efficient distribution of (scarce) resources.

¹⁴ In this analysis, home care and private care are used as synonyms for informal care.

¹⁵ See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change, p. 9 et seq.</u>

¹⁶ Ibid., p. 4 et seq.

¹⁷ Ibid., p. 7 et seq.

¹⁸ See European Commission / Social Protection Committee (2021), Long-term care report. Trends, challenges and <u>opportunities in an ageing society</u>, p. 18. The ageing of European society is demonstrated in particular by the 88% increase in the number of people aged 80 and over, from 26.6 million in 2020 to 49.9 million in 2050; see European Commission / Social Protection Committee (2021), Long-term care report. Trends, challenges and opportunities in an ageing society, p. 18.

¹⁹ Federal Statistical Office (2022), <u>Higher mean age of women at birth of first child</u>.

²⁰ Without taking migration into account.

²¹ See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change</u>, p. 7.

²² Aged between 20-64.

²³ See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change, p. 9 et seq.</u>

²⁴ Kochskämper (2017), <u>Alternde Bevölkerung: Herausforderung für die Gesetzliche Kranken- und für die soziale</u> <u>Pflegeversicherung</u>, p. 5.

in need of long-term care in 2020, up to 8.3 million people are forecast to need long-term care in 2060 - assuming a relatively strong increase in life expectancy.²⁵

Increasing individualisation

Furthermore, increasing individualisation is evident, which can be seen in a change in household structure, for example: While the number of households in the EU is going up, the average size of households is going down.²⁶ In the period from 2010 to 2019, the number of households in the EU-27 increased by 13 million.²⁷ Of these, one third were single-person households in 2019 - and the trend is upwards.²⁸ Consequently, more and more people over 65 will live in single-person households.²⁹ Accordingly, families will increasingly be living apart. This in turn may mean that home (long-term) care can be provided to a lesser extent by relatives.³⁰

Increasing mobility

In addition, increasing mobility, migration from third countries and freedom of movement between Member States are having an effect. Although this may help to counteract the decline in population size and the progressive ageing of a society, it can also have the opposite effect in some regions. This development is particularly problematic for remote and rural areas, where there is an increasing lack of care coverage to meet demand.³¹

Other developments

Women continue to provide the majority of informal care.³² At the same time, the female employment rate has risen significantly in recent years.³³ These developments will also have an impact on informal care. Furthermore, the increasing demand for capable staff, most notably in the formal long-term care sector, will probably not be met at present either, due to the shortage of skilled workers.³⁴

²⁵ See Barmer-Pflegereport (2021), <u>Graphs</u>, Graph 1: Zahl der Pflegebedürftiger steigt rasant. An increase in dementia is also predicted in all Member States, see Alzheimer Europe (undated), <u>Prevalence of dementia in Europe</u>. This is exactly what usually involves a high level of care.

See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change</u>, p. 11.

²⁷ Ibid.

²⁸ Ibid. This corresponds to an increase of 19% compared to 2010.

²⁹ Ibid.

³⁰ The willingness and obligation to care for relatives has a strong cultural component and differs, sometimes significantly, between Member States. It is also shaped by the organisation of the care system in the respective Member States, which in turn is significantly influenced by the so-called welfare state model. In this regard, there is a distinction between the social-democratic, conservative, Mediterranean and liberal welfare states according to whether they ascribe a more decisive role to the state and/or the family or the market. See for example Federal Ministry of Labour, Social Affairs, Health and Consumer Protection of the Republic of Austria (2019), <u>Zukünftige Finanzierung der Langzeitpflege</u>. <u>Ansatzpunkte für Reformen</u>, p. 29-82 or Kraus et al. (2020), <u>Pflegesysteme im internationalen Vergleich</u>, in: Jacobs et al. (Eds.), Pflege-Report 2020, p. 23- 37. In some Member States there is even an obligation to provide informal care for family members. See European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, challenges and opportunities in an ageing society, p. 78.

³¹ See European Commission / Social Protection Committee (2021), <u>Long-term care report. Trends, challenges and</u> <u>opportunities in an ageing society</u>, p. 19.

³² See also section 2.2 below.

³³ See European Commission / Social Protection Committee (2021), Long-term care report. Trends, challenges and <u>opportunities in an ageing society</u>, p. 19.

³⁴ See <u>Report from the Commission (2020) to the European Parliament, the Council, the European Economic and Social</u> <u>Committee and the Committee of the Regions on the impact of demographic change, p. 20.</u>

2.2 The different forms of care and definition of "informal care"

Distinguishing the different forms of care

The care of individuals may be temporary or take place over a longer period of time. It can also involve people of all ages who suffer from physical and mental limitations or disabilities and are dependent on support to cope with everyday life.³⁵ The concept of care also includes childcare, which is why this will also be covered by the European care strategy.³⁶

Although people of all ages may need care, demographic change is substantially increasing the need for long-term care, especially among the elderly.³⁷ Care can be provided by (specialised) staff in hospitals, retirement homes, rehabilitation facilities or in the outpatient (home) environment. This is called "formal" care.³⁸ However, care can also be provided "informally", i.e. by relatives or friends.³⁹

Definition of "informal care"

When it comes to the term "informal care", there are already many different definitions. It should be noted that the concept of "informal care" is significantly shaped by country and culture.⁴⁰ This is because in some Member States it is expected or taken for granted that the family will take care of relatives at home.⁴¹ At the same time, informal care can also be motivated by altruism and reciprocity⁴² and can be provided by friends, neighbours or others in addition to the family.⁴³ A close (emotional) relationship between the person being cared for and the informal carer⁴⁴ is characteristic of this care arrangement.⁴⁵ As a rule, informal carers also have no corresponding professional training or qualifications.⁴⁶

The typical tasks of informal carers cover personal care, including organising and supervising the taking of medication, but also, above all, doing everyday things such as going shopping, doing the laundry and providing company for the person in need of care. Identifying themselves as informal carers is difficult for family members in that they usually carry out everyday tasks.⁴⁷

³⁵ See Eurofound (2020a), <u>Long-term care workforce: Employment and working conditions</u>, p. 3.

³⁶ See Commission Document, p. 1.

³⁷ See Eurofound (2020a), <u>Long-term care workforce: Employment and working conditions</u>, p. 3. The proportion of people in need of care rises sharply with age. See figures from Germany: Demografieportal (undated), <u>Altersspezifische</u> <u>Pflegequoten</u>.

³⁸ See Eurofound (2020a), Long-term care workforce: Employment and working conditions, p. 3.

³⁹ Ibid.

⁴⁰ See Zigante (2018), <u>Informal care in Europe</u>. <u>Exploring Formalisation</u>, <u>Availability and Quality</u>, p. 10.

⁴¹ Ibid.

⁴² Ibid.

⁴³ See UNECE (2019), <u>The challenging roles of informal carers</u>, p. 3.

⁴⁴ Defined in part as those who normally care for someone with a long-term illness, disability or long-term care need on an unpaid basis. This take place outside the professional context. See Eurocarers (2018), <u>Enabling carers to care – An EU</u> <u>Strategy to support and empower informal Carers.</u>

⁴⁵ See European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends, challenges and opportunities in an ageing society</u>, p. 77.

⁴⁶ Ibid.

⁴⁷ For example, a wife continues to care for her dependent husband by doing everyday tasks such as cooking; see OECD (2022), <u>Supporting informal carers of older people</u>: <u>Policies to leave no carer behind</u>, p. 24.

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All this suggests that establishing an EU-wide definition of informal care will be a challenge. It is, however, necessary so that European (care) targets can be meaningfully defined and care needs identified and then verified.⁴⁸

In this assessment, informal long-term care of the elderly is understood to mean care that is provided by family members, for an extended period,⁴⁹ usually on an unpaid basis and in the home environment, and without which the individuals being cared for would be unable to cope with their daily lives.

2.3 Opportunity costs and challenges in the informal care sector

In many Member States, strict conditions must be met before someone can enter a publicly funded long-term care facility.⁵⁰ Informal care is then a prima facie "cheaper" alternative for the individual, be it for the person in need of care or for the informal carers - especially family carers - but from an overall perspective also for society.

From an individual perspective, this is not necessarily the case because informal carers are confronted most notably with so-called opportunity costs. These are costs that arise due to the partial or complete abandonment of professional activity, e.g. lost income, career opportunities or pension rights. In addition, informal carers may themselves be affected by illness and other negative effects on their private lives as a result of providing care,⁵¹ although the individual challenges will of course depend on the respective life situation. However, it is the case that there is often a lack of (financial) recognition of those care services.⁵²

Like formal care, informal care has a strong gender-specific component because the vast majority of informal care is provided by women - usually (well) over 50%.⁵³ The gender difference is most pronounced in the 45-64 age group.⁵⁴ Women are not only more often involved in informal care, but also make a greater contribution in terms of the number of hours invested.⁵⁵

2.4 EU competences and opportunities for influence

General

EU competences are basically determined according to the "principle of conferral" which states that the EU will only act if the Member States have authorised it to do so.⁵⁶ The EU's competences in health policy are in turn limited by the Member States' responsibility for health care, which is guaranteed under primary law^{57,58} Member States are responsible for the organisation and delivery of health and

⁴⁸ On this, see section 3.2.

⁴⁹ Usually more than three months.

⁵⁰ See Zigante (2018), Informal care in Europe. Exploring Formalisation, Availability and Quality, p. 7.

⁵¹ See UNECE (2019), <u>The challenging roles of informal carers</u>, p. 7. At the same time, it should also be mentioned that informal care does not have to be fundamentally burdensome. Informal carers may experience a positive benefit from giving something back to family members, friends or neighbours.

⁵² Ibid., p. 9.

⁵³ See European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, <u>challenges and</u> <u>opportunities in an ageing society</u>, p. 78 et seq.

⁵⁴ Ibid., p. 79.

⁵⁵ Ibid., p. 77.

⁵⁶ Art. 5 (1) and (2) TEU.

⁵⁷ Art. 168 (7) TFEU.

⁵⁸ See Stockebrandt (2021), <u>cepInput Three steps towards a European Health Union</u>, p. 3.

social care.⁵⁹ Care systems are designed at national level.⁶⁰ Although the EU has little legislative power in these areas, its influence on national health and care systems should not be underestimated.⁶¹

Social Policy

With regard to social policy, the EU can promote cooperation between Member States⁶² and adopt directives containing minimum requirements⁶³ in certain areas.⁶⁴ The EU did the latter in 2019 with, among other things, the Directive on work-life balance for parents and carers⁶⁵ [(EU) 2019/1158].⁶⁶ This Directive contains minimum requirements on leave and flexible working arrangements for family carers.⁶⁷ Specifically, it provides that family carers are entitled to five days' leave per year to care for their relatives.⁶⁸ In addition, they have a right to apply for flexible working arrangements⁶⁹ and, in this regard, are entitled to greater protection from dismissal⁷⁰.

In addition, the EU can support Member States in the modernisation of social protection systems^{71,72} This may, in principle, relate to all areas concerning social security,⁷³ including, in particular, the long-term financial viability of pension systems, gender equality and the guarantee of high-quality health care that can be financed in the long term.⁷⁴ In these areas, the so-called open method of coordination is to be used.⁷⁵ This is a procedure for coordination in those policy areas in which the EU has no or only limited competences and it can encourage "voluntary parallel behaviour" by the Member States.⁷⁶

⁶³ Art. 153 (2)(b) TFEU.

⁵⁹ See also European Commission (2018), <u>Communication on enabling the digital transformation of health and care in the Digital Single Market</u>, p. 2 et seq.

⁶⁰ See Commission Proposal, p. 3.

⁶¹ For example, with regard to preventive budgetary control within the framework of the so-called European Semester. This control also includes the health systems, for which in some cases very concrete suggestions for reform - e.g. improving the efficiency of care - are given; see Kingreen, in: Calliess/Ruffert (Eds.), TEU/TFEU, 6th Edn. 2022, Art. 168, para. 38 citing further references. The EU has also addressed demographic changes and the impact on care systems in the past. Most recently, the EU Commission's 2021 Green Paper on an Ageing European Society launched a debate on how lifelong learning, physical as well as social activity and nutrition can contribute to a healthy lifestyle, prevent disease and enable "healthy ageing". See European Commission (2021), Green Paper on Ageing. Fostering solidarity and responsibility between generations.

⁶² Art. 153 (2)(a) TFEU.

⁶⁴ Langer, in: von der Groeben/Schwarze/Hatje (Hg.), Europäisches Unionsrecht, 7th Edn. 2015, Art. 153, para. 50 et seq.

⁶⁵ Directive (EU) 2019/1158 of the European Parliament and of the Council on work-life balance for parents and carers - hereinafter: Directive (EU) 2019/1158.

⁶⁶ Based on Art. 153 (2) (b) in conjunction with Art. 153 (1) (i) TFEU.

⁶⁷ See Art. 1 Directive (EU) 2019/1158.

⁶⁸ See Art. 6 Directive (EU) 2019/1158.

⁶⁹ See Art. 9 (1) Directive (EU) 2019/1158.

⁷⁰ See Art. 12 (1) Directive (EU) 2019/1158.

⁷¹ Art. 153 (1)(k) TFEU.

⁷² Art. 153 (2)(a) TFEU.

⁷³ See Langer, in: von der Groeben/Schwarze/Hatje (Eds.), Europäisches Unionsrecht, 7th Edn. 2015, Art. 153, para. 43.

⁷⁴ Ibid.

⁷⁵ Ibid., para. 44.

⁷⁶ See Kingreen, in: Callies/Ruffert, EUV/AEUV, 6th Edn. 2022, Art. 168, para. 24. For example, the European exchange format for electronic health records and the necessary IT infrastructure for cross-border exchange came into being in an - admittedly lengthy and laborious - voluntary process of cooperation between the Member States; see Rothe / Stockebrandt (2019), cepPolicyBrief 15/2019. The IT infrastructure was initially called "eHealth Digital Service Infrastructure" (eHDSI) and is now continued under the name "MyHealth@EU"; see EU Commission (2022), Electronic cross-border health services.

Health policy

With regard to health policy, the open method of coordination is again relevant.⁷⁷ For example, in June 2001, the European Council issued a mandate, in accordance with the open method of coordination, to prepare an initial report on orientations in the field of health care and care for the elderly.⁷⁸ Although this method is a non-binding procedure, it allows EU-wide guidelines and indicators to be developed and agreed upon, which can then be used to regularly monitor and evaluate whether previously agreed targets are being met.⁷⁹ The EU4Health financial programme⁸⁰ can be used to finance promotion and support measures.

Other areas

Ultimately, both the Council [Art. 292 (1) and Art. 168 (6) TFEU] and the Commission [Art. 292 (4) TFEU] can always make recommendations. Although these do not legally bind the Member States, the recommendation has already been used as an instrument in health policy⁸¹ and also for the joint management of the COVID 19 pandemic⁸².

3 Impulses for a future EU care policy

Thus, the EU has individual competences, or at least various ways to exert influence, which allow it to support care in the Member States. The following section sets out various impulses for helping to strengthen informal care in the EU. At the same time, this study focuses on the situation for informal carers and ways to support them.

3.1 Strengthening work-life balance for informal carers

Ideally, there should be freedom of choice between informal and formal care, depending entirely on individual circumstances and the capabilities of those involved, as well as other factors. In the best case, a care system should allow for both. Informal care is often regarded as a "cheaper" alternative to formal home or residential care.⁸³ However, it is necessary to bear in mind that it may result in the loss of tax revenue and social security contributions⁸⁴ as well as higher social costs, e.g. in the form of lower pensions⁸⁵. These could in turn make state support necessary.⁸⁶ As a result of the physical and psychological demands, informal carers can become ill,⁸⁷ which in turn leads to more social costs. The minimum requirements of Directive (EU) 2019/1158 have taken the initial steps towards improving

⁷⁷ Art. 168 (2) TFEU.

⁷⁸ See European Council (2001), <u>Conclusions of 15-16 June</u>, para. 43.

⁷⁹ See overall Niggemeier, in: von der Groeben/Schwarze/Hatje (Eds.), Europäisches Unionsrecht, 7. Edn. 2015, Art. 168, para. 25.

⁸⁰ See EU4Health 2021-2027 - A vision for a healthier European Union.

⁸¹ See Stockebrandt (2021), <u>cepInput Three steps towards a European Health Union</u>, p. 8.

⁸² See Stockebrandt (2021), cepInput Three steps towards a European Health Union, p. 9 et seg. – in particular Footnote 51. For related problems, see also Stockebrandt / De Petris (2022), cepInput Strengthen Democratic Oversight of HERA, p. 3 with particular reference to Footnote 5.

⁸³ See Geyer / Korfhage (2015), Long-term Care Insurance and Carers' Labor Supply – A Structural Model, p. 1178. ⁸⁴ Ibid.

⁸⁵ On this see the sub-section below entitled "Supporting Member States with old-age provision and pensions".

⁸⁶ This is conceivable if informal carers suffer from poverty as a result, for example.

⁸⁷ For previous findings of the impact of informal care work on the health of informal carers, see Footnote 120.

work-life balance for carers and these may start to have an impact across the EU.⁸⁸ However, they will not completely solve the challenges outlined above - further steps are needed.

Meeting the need for information

The degree of care required by the person to be cared for significantly determines the time and intensity associated with informal care. Carers frequently have great difficulty in achieving work-life balance.⁸⁹

In addition to the minimum requirements of Directive (EU) 2019/1158, it will also be crucial to provide informal carers with comprehensive information about their rights and other support measures because they are often unaware of what claims they are actually entitled to.⁹⁰ This problem has also been seen in Germany, for example, where, according to a study by the social federation VdK, care benefits are often not claimed and are thus forfeited by the beneficiary, mainly due to a lack of awareness and complex application forms.⁹¹ The EU should therefore optimise existing⁹² multilingual information portals and continuously ensure that the information is up-to-date. These information portals would then allow EU citizens easy EU-wide access to the necessary information about their rights and the national contact points.⁹³ In addition, the EU should draw more attention to these information portals EU-wide and also regularly provide information about them via low-threshold information channels, e.g. in social media.

Further development of Directive (EU) 2019/1158

Before the COVID 19 pandemic, an average of 5.4% of employed workers in the EU-27 normally worked from home. While this proportion had remained relatively constant in the years prior to the pandemic, the proportion of employed workers who sometimes worked from home had increased from 6% to 9% in the period from 2009 to 2019. The proportion of self-employed working from home had also increased.⁹⁴ In the first phase of the pandemic, the proportion of employees working from home increased to an average of 37% in the EU-27.⁹⁵ The Directive (EU) 2019/1158, which was adopted prior to this, does not currently reflect these developments. Mobile working and working in a home office have created new opportunities to improve work-life balance for carers. These must be encouraged by reforming Directive (EU) 2019/1158.

Supporting Member States with old-age provision and pensions

As a result of the demographic changes, not only has there been an increase in the number of people in need of care, but also a fall in the number of people in employment. This may be problematic for

⁸⁸ According to Art. 20 (1), Member States had to transpose the Directive by 2 August this year.

⁸⁹ See Fischer / Müller (2020), <u>Bessere Vereinbarkeit von Beruf und Pflege kann Zielkonflikt zwischen Renten- und Pflegepolitik lösen</u>, p. 855.

⁹⁰ See UNECE (2019), <u>The challenging roles of informal carers</u>, p. 9.

⁹¹ See Sozialverband VdK (2022), <u>Nächstenpflege: Alleingelassen und in Bürokratie erstickt. Zentrale Studienergebnisse und Forderungen des Sozialverbands VdK</u>, p. 3 et seq.

⁹² See e.g. the EU website "<u>Your rights country by country</u>".

⁹³ For existing information portals and databases, see also Footnotes 129 and 130.

⁹⁴ See overall Eurostat (2020), <u>How usual is it to work from home?</u>

⁹⁵ Eurofound (2020b), <u>Living, working and COVID-19. First findings – April 2020</u>, p. 5.

national economies and the preservation of pay-as-you-go pension systems - such as Germany's statutory pension insurance.⁹⁶

However, this is not only significant for the economies of the Member States, but also of course affects every individual. Thus, for example, the opportunity costs for women aged 45-64, who spend more time providing informal care than younger women, and than men in general, take two forms: Direct opportunity costs include lost wages amounting to an average of € 25,800 gross.⁹⁷ Indirect opportunity costs also arise in the sense that it is difficult to find employment after providing informal care because the informal carer will have been out of the regular labour market for some time.⁹⁸ This in turn has an impact on their pension entitlements, which is also part of the indirect opportunity costs.⁹⁹ Although most Member States allow for pension credits for informal carers, their work regularly results in lower pensions than a traditional full-time job subject to social security contributions.¹⁰⁰ Member States must resolve various conflicts of interest in this regard: in particular, promoting or expanding informal care may conflict with equal access to the labour market. The EU, for its part, can (only) provide support through concrete recommendations related to the respective Member States.¹⁰¹

3.2 Common definitions and targets

The situation in different Member States

About 20% of Member States have a statutory definition of informal care.¹⁰² These usually focus on a close connection between the person in need of care and the informal caregiver.¹⁰³ Thus, for example, in France, it has been the case since 2015 that a person is considered to be an informal carer if he or she either lives with the person in need of care or the connection between the two is characterised by a close and stable relationship.¹⁰⁴ Accordingly, care serves the frequent and regular fulfilment of all or certain tasks of daily life.¹⁰⁵ The same also applies to the legal definitions in Finland and Belgium, which

¹⁰⁴ Ibid.

⁹⁶ On the issue of how demographic developments and the retirement of the baby boomers in the mid-2030s will put pressure on Germany's pay-as-you-go statutory pension insurance - including possible reform options - see Deutsche Bundesbank (2022), <u>Monthly Report: Wie Rentenreformen wirken könnten</u>.

⁹⁷ The average loss of income for men in the same age group is estimated at € 27,000. See European Commission / Social Protection Committee (2021), p. 86. Men often have a higher income at the time of the care decision - as in this numerical example - which is why women are more likely to opt for informal care and traditional work-sharing models. See Offermanns / Schweiger (2018), <u>Status quo Pflege - Zur (Un)Vereinbarkeit von informeller Pflege und Beruf</u>, in: Behrens et al. (Eds.), Familie – Beruf – Karriere. Daten, Analysen und Instrumente zur Vereinbarkeit, p. 187.

⁹⁸ See European Commission / Social Protection Committee (2021), <u>Long-term care report. Trends, challenges and opportunities in an ageing society</u>, p. 85.

⁹⁹ Ibid. In some cases, there is thought to be a causal relationship between the provision of informal care and women's retirement. In Germany, for example, it has been shown that women take advantage of early retirement opportunities in order to be able to provide informal care for relatives. In addition, the conflict of interest between raising the retirement age and the provision of informal care becomes clear. The latter decreases for women as the retirement age goes up. See Fischer / Müller (2020), Bessere Vereinbarkeit von Beruf und Pflege kann Zielkonflikt zwischen Renten- und Pflegepolitik lösen. It should be noted, however, that the results refer to the social security system in Germany and are thus not directly transferable to other Member States - partly due to country-specific and cultural differences in care.

¹⁰⁰ European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, <u>challenges and opportunities</u> <u>in an ageing society</u>, p. 86.

¹⁰¹ See also, by way of example, Bundeszentrale für politische Bildung (2020), <u>Empfehlungen zur Ausgestaltung der</u> <u>Rentensysteme</u>.

¹⁰² OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 24.

¹⁰³ Ibid.

¹⁰⁵ At the same time, it must not constitute the exercise of a professional activity.

likewise emphasise a close private relationship between care recipient and informal caregiver,¹⁰⁶ but the persons concerned do not necessarily have to be in a close relationship with each other.¹⁰⁷

The close relationship of the persons concerned plays an absolutely central role, especially in the southern European Member States. Thus, for example, legislation in Spain stipulates that a person must at least be a third degree relative, and have lived with the person in need of care for at least one year, to be considered an informal caregiver.¹⁰⁸ An exception exists where the person in need of care is living in a (rural or remote) area where care provision is poor.¹⁰⁹ In 2019, Portugal legislated for two types of informal carer - "principal carer" and "non-principal carer" -¹¹⁰, so that the persons concerned had more rights and in some cases could receive financial remuneration.¹¹¹

In both cases, recognition is followed by advantages in the social security systems, e.g. with regard to further training or psychological support.¹¹² Since the access criteria for obtaining the status of informal carer are quite restrictive, it does not cover all informal carers. Overall, however, the developments in Portugal and Spain show that these Member States have recognised the socio-political relevance of informal care.

In other Member States, the closeness of the relationship often plays a less important role. Instead, it is the number of hours or the type of care that counts.¹¹³ Thus, registered informal carers in Germany who are providing home-based long-term care for at least 14 hours per week, will receive support¹¹⁴.¹¹⁵ In the northern European Member States¹¹⁶ and the Netherlands, local authorities determine the criteria for supporting informal carers. These criteria regularly focus on the number of hours worked and the type of care.¹¹⁷

¹⁰⁶ See OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 24.

¹⁰⁷ Ibid.

¹⁰⁸ Ibid., p. 25.

¹⁰⁹ Ibid., p. 25.

¹¹⁰ The status of "principal carer" is only granted to close family members who live in the same household as the person in need of care. These persons do not receive direct remuneration if they earn other income, e.g. through professional activities, or receive a pension or unemployment benefit. Furthermore, the household concerned must not exceed a defined income level. A family member providing care who does not live in the same household as the person in need of care is usually classified as a "non-principal carer". This does not necessarily have to be done free of charge but may be remunerated. See European Commission / Social Protection Committee (2021), Long-term care report. Trends, challenges and opportunities in an ageing society, p. 123 and OECD (2022), Supporting informal carers of older people: Policies to leave no carer behind, p. 25.

¹¹¹ See OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 25 and European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, <u>challenges and opportunities in an</u> <u>ageing society</u>, p. 123.

¹¹² See European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, <u>challenges and</u> <u>opportunities in an ageing society</u>, p. 123 et seq.

¹¹³ See OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 25.

¹¹⁴ This takes the form of benefits from the long-term care insurance funds. Furthermore, informal carers in this category who are not providing care as their job, are covered by health and long-term care insurance. Provided that the person receiving care has a care need of at least level 2 (out of 5), the long-term care insurance will pay contributions into the statutory pension scheme for informal carers according to the time spent on care. See Federal Ministry of Health (2021), <u>Pflegegrade</u> and Pflege.de (2022), <u>Beruf, Familie & Pflege vereinbaren</u>. For more on pension entitlement opportunities from informal care, see Deutsche Rentenversicherung (2022), <u>Pflege von Angehörigen lohnt sich auch für die Rente.</u>

¹¹⁵ See OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 25.

¹¹⁶ With the exception of Finland.

¹¹⁷ See OECD (2022), <u>Supporting informal carers of older people: Policies to leave no carer behind</u>, p. 25.

EU-wide definition

The EU - as has already been stated - has no competence to change the design of the care systems of the Member States by law. It cannot therefore provide a definition. Nevertheless, the EU should support Member States in developing an EU-wide definition of informal care through voluntary cooperation. Such a definition could then be agreed by way of a Council recommendation¹¹⁸.¹¹⁹

Identify causalities and define common targets

The EU can also develop a more accurate picture of informal care in the EU by funding further studies. Such basic research may generate comparable EU-wide data which could then also be used to improve the evaluation of political decisions. It is especially necessary to identify causalities¹²⁰ in order to facilitate the development of instruments that are as accurately targeted as possible and enable agreement on verifiable targets.

Furthermore, the EU should set measurable targets¹²¹ in the area of informal care, for which the EUwide definition mentioned above can serve as a "basis of measurement". The common targets could also be agreed in a Council recommendation. For example, it is conceivable that a certain percentage of informal carers in the EU will (re-)enter full-time employment by 2050¹²². At the same time, the conflict of interest between care policy and employment or pension policies should be mitigated. In this context, it is important to ensure a better work-life balance for carers and, at the same time, give greater recognition to the achievements of informal carers, e.g. in the form of acquired pension rights.

3.3 Learning from pioneers in the field of care

Encourage exchange of best practices

One contribution that the EU can make, which should not be underestimated, is to support cooperation between Member States, in particular through the exchange of best practices¹²³. This includes approaches and/or activities which research and evaluation have shown to be effective and transferable.¹²⁴ The EU can promote exchange between Member States and with other countries, for

¹¹⁸ Art. 292 (1) TFEU.

¹¹⁹ A similar approach was taken, for example, with the EU-wide recognition of COVID-19 tests; see Stockebrandt (2021), <u>cepInput Three steps towards a European Health Union</u>, p. 9 et seq. - especially Footnote 51. For related problems, see also Stockebrandt / De Petris (2022), <u>cepInput Strengthen Democratic Oversight of HERA</u>, p. 3, with particular reference to Footnote 5.

¹²⁰ Home care can have a negative impact on the health of informal carers. See European Commission / Social Protection Committee (2021), <u>Long-term care report</u>. <u>Trends</u>, <u>challenges and opportunities in an ageing society</u>, p. 85. However, due to the lack of data, accurate recording of causalities is a challenge. Previous studies have come to different conclusions in this regard. So far, there is only consensus on the fact that providing comprehensive care can have a noticeable impact on the physical and mental health of informal carers. See Zigante (2018), <u>Informal care in Europe</u>. <u>Exploring Formalisation</u>, <u>Availability and Quality</u>, p. 15.

¹²¹ A possible benchmark could be the so-called Barcelona targets for childcare. In 2002, the so-called Barcelona targets set out standards for childcare. By 2010, for example, Member States should be able to provide childcare places for at least 90% of all children between the age of three and the mandatory school age. See European Council (2002), <u>Barcelona</u> <u>European Council, 15 and 16 March 2022</u>, p. 12.

¹²² The year 2050 was chosen because by then the demographic developments in the EU will probably have had their full effect. On this, see section 2.1.

¹²³ Also referred to as "good practice" or "best practice".

¹²⁴ See e.g. European Commission (2021), <u>What are "good practices"?</u>

example through information portals, by bringing stakeholders into direct contact¹²⁵ ¹²⁶ or by funding studies. Overall, this allows Member States to learn from pioneers in the field of care - be it other Member States, third countries, certain (European) cities or successful practices.

Example: Digital support for care

In this context, it is particularly useful to learn from countries that use digital support for care. Finland is one of the pioneers in this field.¹²⁷ Digital support is also useful with regard to the information needs of informal carers.¹²⁸ For example, the British association "Carers UK" offers an information platform where digital products and online resources can be found. E-learning courses are designed to help prevent crises brought about by the care situation. In addition, the information platform offers a variety of useful applications, e.g. for expanding support networks or providing information on financial support.¹²⁹ The Swiss Federal Office of Public Health is also focusing on improving the provision of information and support services via a specially designed database.¹³⁰

Other possibilities for exchange

In addition to digital applications, traditional methods also bring added value and can be shared as best practices. In Germany, for example, there is the so-called care telephone¹³¹ which provides advice to informal carers.¹³² In addition, the exchange should also include building the skills of informal carers¹³³ as well as specific aspects of (daily) care. This includes, for example, experience with smart care beds that can create a better lying position if necessary, or with different types of (care) robots capable of performing a variety of functions.¹³⁴ There are still a number of ethical, data protection and

¹²⁵ See e.g. the "<u>Public Health Best Practice Portal</u>".

¹²⁶ This is regularly part of the six-month programme of the respective Council Presidency; see, e.g., the examples (on a completely different topic) of the French Council Presidency: "Seminar on the exchange of best practices on counter-terrorism sanctions" and "Ministerial conference on combating homelessness".

¹²⁷ For example, video calls are used there - in addition to home visits - for providing care. See Deutschlandfunk Kultur (2019), <u>Digitale Krankenschwestern in Finnland. Videoanrufe statt Hausbesuche</u>.

¹²⁸ In section 3.1, we pointed out that informal carers often do not have enough information to support them.

¹²⁹ For full details see UNECE (2019), <u>The challenging roles of informal carers</u>, p. 15.

¹³⁰ See Federal Office of Public Health (2022), Suche Modell guter Praxis – betreuende Angehörige and UNECE (2019), <u>The challenging roles of informal carers</u>, p. 15

¹³¹ Operated by the Federal Ministry for Family Affairs. For full details see Bundesministerium für Familie, Senioren, Frauen und Jugend (2015), <u>Das Pflegetelefon: schnelle Hilfe für Angehörige</u>.

¹³² See UNECE (2019), <u>The challenging roles of informal carers</u>, p. 15.

¹³³ Thus, by building skills, a carer can improve their knowledge and capabilities in such a way that they are better able to protect themselves against the physical and psychological effects and crisis situations and thus provide better care overall. See also UNECE (2019), <u>The challenging roles of informal carers</u>, p. 15.

¹³⁴ Various applications are possible for care robots. Firstly, in the area of health, they can carry out physical and mental tasks. In addition, they can also complete everyday tasks. When classifying care robots, it is important to distinguish between those capable of social interaction, and service robots, whose main function is simply the completion of tasks. The former have a human component to their communication. For full details see Janowski et al. (2018), <u>Sozial interagierende Roboter in der Pflege</u>. In: Bendel (ed.), Pflegeoboter, p. 64 et seq.; Lernende Systeme (2022), <u>Al zur Unterstützung in der Pflege</u> as well as kma online (2019), <u>Pflegeroboter: Eine Kosten-Nutzen-Analyse</u>.

privacy-related issues, especially in the case of care robots with built-in artificial intelligence,¹³⁵ for which EU-wide exchange would be useful.¹³⁶

4 Conclusion

Europe's population is getting older. That is just one of the reasons why European care systems will come under dramatic pressure in the coming years and face major socio-political and financial challenges. Since the Member States have different, country-specific preferences, it is appropriate that the care systems continue to be designed at national level and that the relevant competences lie and remain with the Member States. Nevertheless, an intelligent EU care strategy to support Member States could be worthwhile. For example, care policy targets will inevitably interact with other EU targets, particularly with regard to work-life balance and gender equality. In the best case, this will facilitate the development of instruments that are better overall for achieving the various EU targets. The voluntary harmonisation of definitions and an accurate understanding of the nature and extent of informal care in the EU is necessary and appropriate in this regard. The EU can also promote exchange between Member States and provide back-up resources.

This analysis has identified various impulses for improving the situation of informal carers and informal care as a whole:

Impulse 1 - Strengthen work-life balance for carers. It is apparent that EU citizens are often unaware of possible (financial) support from the Member States and thus fail to claim benefits. In this respect, there is a need for information, which can also be met by way of EU support. In addition, the Directive on work-life balance for parents and carers [(EU) 2019/1158] should be adapted. An important starting point here is to ensure more flexible employment models, especially since higher opportunity costs for men usually lead to women opting for informal care and (partially) giving up their employment. Finally, the EU should support Member States in the area of old-age provision and pensions because demographic changes are putting pay-as-you-go systems under pressure. In addition, the conflict of interest between care and pension policies must be taken into account. In view of demographic changes, Member States are walking a tightrope. Thus, on the one hand, they have been relying heavily on informal care whilst, on the other, the number of people in employment is decreasing due to the ageing population and simultaneous decline in the birth rate. Although Member States are primarily responsible, the EU can play a supporting role.

Impulse 2 - Common definition and targets. Better policy evaluation requires data that is comparable EU-wide. EU-wide data is also necessary in order to develop instruments that are as tailored as possible and to agree on verifiable targets. However, as the nature and extent of informal care in the EU is currently difficult to measure, there is a need for common definitions which will provide a basis of measurement for the formulation of concrete targets. Although the EU does not have the competence

¹³⁵ For example, robots equipped with cameras, sensors and microphones have insights into the private and personal sphere of the person in need of care. The robot can use the data it collects to help it to adapt to different situations. However, this gives rise to questions such as what happens to the data that is collected and can it be passed on. See Kreis (2018), <u>Umsorgen, überwachen, unterhalten – sind Pflegeroboter ethisch vertretbar?</u> In: Bendel (Ed.), Pflegeroboter, p. 217 and Tagesschau (2020), <u>Mein Helfer, der Pflegeroboter</u>. In this context, it would seem appropriate to establish, in writing, the individual will of the person in need of care. Voluntary cooperation at EU level could also be used in this respect. Thus, a standardised EU form could be developed ensuring that data protection requirements under European law are met in a legally secure manner.

¹³⁶ On artificial intelligence in care in general, see: Acatech (2021), <u>So kann KI in der Pflege unterstützen:</u> <u>Anwendungsszenario zeigt Chancen und Grenzen.</u>

to legislate on definitions, these can be developed through voluntary cooperation between the Member States. The EU can and should then set measurable targets in the area of informal care. Both the common definitions and the targets should be agreed in a Council Recommendation. The nonbinding Recommendation is an instrument which respects the competences of the Member States and at the same time provides a basis for joint (voluntary) action at EU level. Thus, EU targets can be formulated that are then also verifiable. A specific example would be the agreement of targets for the return of informal carers to the labour market.

Impulse 3 – **Learning from pioneers in the field of care.** One practical contribution that the EU can make, which should not be underestimated, is to support cooperation between Member States. This can be done most notably by exchanging best practices via central information portals, organised professional exchanges or even the funding of studies. Overall, this allows Member States to learn from pioneers in the field of care - be it other Member States or third countries.



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