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WELFARE STATE IDEOLOGIES AND LONG-TERM CARE REGIMES: CHALLENGES OF WORKING AGE CARERS WITH DEPENDENT RELATIVES IN MACEDONIA

Abstract

The aim of the paper is twofold: to analyse to what extent the concept of “reconciliation between professional and private life” fits into the tradition and scope of the long-term care (LTC) regimes in Europe, as well as to provide insight into the challenges of working age carers in Macedonia. The initial hypothesis of the paper is to identify whether the lack of support towards carers in some of the European long-term care regimes is associated with the tradition and/or welfare ideology in which LTC systems were created. For that purpose, a comparative analysis will be undertaken of LTC schemes in four different welfare state regimes (Esping-Andersen, 1990) i.e. in Sweden, Germany, UK and Italy. The analysis will take into consideration the founding principles of the LTC regimes, welfare ideology as well as the scope of support provided to carers in the respective countries.

The second part of the paper will provide insight into challenges faced by working age carers with dependent relatives in Macedonia. This country case study will provide insight into the challenges faced by the caregivers due to lack of balance between the overall package of social protection, health and employment measures. Hence, this part will try to support the evidence that in countries where labour market support of the carers' is marginalized, carers' are more vulnerable category, especially in relation to employment and decent living standards.

Key words: welfare state, long-term care, dependency, carers, leaves, cash benefits, benefits in kind.

1. INTRODUCTION: CARERS AND LONG-TERM CARE REGIMES IN EUROPE

There is a wide scope of comparative research related to long-term care regimes, which spans from focus on elderly care¹⁾, formal and informal care²⁾, social care services³⁾, as well as their correlation with employment models⁴⁾. Building on Lamura⁵⁾, Nies⁶⁾ also provides a typology in which former socialist countries are added into a cluster of LTC regime characterized with low demand for care, high provision of informal care and medium/low provision of formal care⁷⁾. Taking into consideration that the main purpose for creation of the long-term care systems was to provide assistance to the cared for persons, it is understandable that most of the existing regimes focus on measures and type of support provided to the dependent persons. Also, in some countries it is difficult to distinguish the main beneficiary of the long term care

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- 1) M. Kraus, T. Czipionka, M. Riedel, E. Mot and P. Willemé, *How European Nations Care For Their Elderly - A New Typology Of Long-Term Care*, Enepri Policy Brief, No. 7, July 2011.
 - 2) F. Bettio and J. Plantenga, "Comparing care regimes in Europe", *Feminist Economics*, 10(1), 2004, pp. 85–113.
 - 3) A. Anttonen and J. Sipilä, "European Social Care Services: Is It Possible To Identify Models?", *Journal of European Social Policy*, 6(2), 1996, pp. 87–100.
 - 4) A. Simonazzi, "Care regimes and national employment models", *Cambridge Journal of Economics*, 33(2), 2009, pp. 211–232.
 - 5) G. Lamura, *Dimensions of future social service provision in the ageing societies of Europe*, Paper presented at the VI. European Congress of Gerontology and Geriatrics, St. Petersburg, Russia, 2007.
 - 6) H. Nies, K. Leichsenring and S. Mak, "The emerging identity of Long-Term Care systems in Europe", In: *Long-Term Care in Europe. Improving policy and practice* (eds. Leichsenring K., Billing J., and Nies H.), Basingstoke, Palgrave Macmillan, 2013, pp. 19–41.
 - 7) K. Schulmann and K. Leichsenring, *Social support and long-term care in EU care regimes*, European Commission's Seventh Framework Programme FP7-SSH-2012-1/No 320333, 2014, Internet, www.mopact.group.shef.ac.uk, 05/04/2016

support, as some of the benefits aimed at cared for persons, may also be beneficial for the carers. Despite the fact that the primary concern of this paper is to analyze regimes according to their focus on carers, still the analysis will be built after investigating variety of long-term care approaches discussed in the literature and their main contribution.

The most widely cited Esping-Andersen's welfare state regime typology (1990)⁸⁾ provides beneficial ground for disentangling political and welfare cross-national variations. While this classification does not bear any long-term care variable, still it provides source for identifying different country-clustered approaches related to decommodification, stratification and public-private mix. Esping-Andersen's⁹⁾ seminal work contributed towards emphasizing the "de-familization of welfare responsibilities" in Scandinavian countries, the norm of "private welfare provisions and limited public responsibilities" in the Liberal camp, "the subsidiary character of state intervention after family capacities are exhausted" in the Conservative model, and "traditional familial welfare responsibilities" in Mediterranean countries.

Other authors building on existing welfare state classifications, and adding the long-term care aspect, outlined additional typologies. Lamura¹⁰⁾ on the basis of carers' perceptions in six countries (Greece, Italy, UK, Sweden, Poland and Germany) identified divide between North West Europe (NWE) and South West Europe (SWE). He outlined perceptible level of service provision (in terms of day care, information, and self-help groups) in Germany, Sweden, and the UK. In the other analyzed countries, he perceived a widespread absence and/or inaccessibility of support (albeit in Italy this was mitigated by the cash for-care schemes).¹¹⁾

As described in Schulmann and Leichsenring¹²⁾, a typology of European long-term care regimes was provided by Nies et al.¹³⁾, focus-

8) G. Esping-Andersen, *The Three Worlds of Welfare Capitalism*, Princeton University Press, Princeton, 1990.

9) G. Esping-Andersen et al., *Why We Need a New Welfare State*, Oxford University Press, Oxford, 2002.

10) G. Lamura, E. Mních, M. Nolan, B. Wojszel, B. Krevers, L. Mestheneos and H. Dohner, "Family Carers' Experiences Using Support Services in Europe: Empirical Evidence from the EUROFAMCARE Study", *The Gerontologist*, Vol. 48, No. 6, 2008, pp. 752–771.

11) *Ibid*, pp. 765.

12) K. Schulmann and K. Leichsenring, *Social support and long-term care in EU care regimes*, European Commission's Seventh Framework Programme FP7-SSH-2012-1/No 320333, 2014, Internet, www.mopact.group.shef.ac.uk, 05/04/2016

13) H. Nies, K. Leichsenring and S. Mak, "The emerging identity of Long-Term Care systems in Europe", In: *Long-Term Care in Europe. Improving policy and practice* (eds. Leichsenring K., Billing J., and Nies H.), Basingstoke, Palgrave Macmillan, 2013, pp. 19–41.

ing on demand and provision of formal and informal care. They identified four long-term care regimes, i.e. Standard care mix; Universal Nordic; Family based, and a Transition regime, ranging from high, medium and low provision of care.

A different approach was taken by Kraus et al.¹⁴⁾, which developed two typologies. The first one, based on 21 EU member states analyses the organization and financing of care. It outlines four groups of countries ranging from highly developed systems and generous public funding (Nordic countries, France and Germany), group of highly developed systems (Bulgaria, Czech Republic, Estonia, Slovakia), through less patient-friendly systems (Hungary, Lithuania, Poland, Romania) and finally moderate financial generosity and moderate organisational depth systems (Austria, England, Finland, Italy, Latvia, Slovenia and Spain)¹⁵⁾. Their other typology focuses on use of care and is based on 14 EU member states. Based on variables, such as: public expenditure on LTC as a share of GDP, private expenditure as a share of LTC spending, informal care recipients 65+ as share of the population 65+, and support for informal care givers, they identified four clusters of systems, namely: Informal care oriented with low private financing; Generous, accessible and formalised; Informal care oriented with high private financing; and High private financing where informal care seems necessity.¹⁶⁾

We can see that few of these regimes (i.e. formal and informal care regimes) were constructed on the basis of lack of existing support provided towards carers. Some may rightly argue that the main purpose of the long-term care systems was not to provide for the carers, but for the dependent persons. Hence, it is understandable that the main focus of analysis on the cared for persons dominate the scientific literature. However, carers' aspect of analysis provides additional insight into the challenges of long-term care systems, as care provision may be a source for greater vulnerability, especially among women, and particularly in relation to carers limited possibilities for employment and/or adequate incomes.

Inadequate provision and lack of measures for reconciliation between private and professional life aimed towards carers was an initial imperative for the analysis in this paper. In this respect, a recent com-

14) M. Kraus, T. Czypionka, M. Riedel, E. Mot and P. Willemé, *How European Nations Care For Their Elderly - A New Typology Of Long-Term Care*, Enepri Policy Brief, No. 7 July 2011.

15) M. Kraus, T. Czypionka, M. Riedel, E. Mot and P. Willemé, *How European Nations Care For Their Elderly - A New Typology Of Long-Term Care*, Enepri Policy Brief, No. 7 July 2011. pg. 3.

16) *Ibid.* pg. 3.

parative synthesis report¹⁷⁾, presents one of the initial attempts in the scientific literature to provide an overview of schemes/regimes existing in the European Union member and candidate countries, as well as in the four European Free Trade Association countries, with the focus on the carers. According to the analysis of 35 countries, this report identified two broad categories of care regimes aimed at carers, defined as:

- a) Developed and mature support schemes for carers and
- b) Underdeveloped support schemes for carers.

The first broad category of developed and mature support schemes contains two subgroups, namely: Countries with relatively universal and comprehensive long-term care support schemes for carers and countries providing provisions mainly to the dependent person and specific support to the carer. Representatives of the former category were identified as: “countries with well-established, long-lasting tradition of LTC; with existing mix between leaves, cash benefits and benefits in kind specifically provided to the carer; with a well-developed public system of in-home care support and with institutional care that represents a significant support for the work-life balance of the carer”¹⁸⁾. Countries that belong to the latter category are mostly those that have specific support towards carers, including: generous leave conditions, well developed institutional care, and cash benefits targeted specifically at the carer. On the other side of the spectrum, are countries belonging to the “familistic” model, where specific provisions for the carers are almost non-existent.¹⁹⁾

Notwithstanding the issues affecting long-term care classifications (i.e. traditions, different socio-economic and demographic contexts, chosen variables, etc.), this paper will try to qualitatively compare different measures offered to carers and their effectiveness in combining private and professional life. In doing so, the analysis will be based on insight into case studies (Sweden, Germany, United Kingdom, Italy and Macedonia), belonging to different care regimes aimed at carers. In addition, this categorization will be compared with the welfare state regime classification of Esping-Andersen (1990), with purpose to analyse possible differentiations from the overall welfare state contours.

17) D. Bouget, S. Spasova and B. Vanhercke, *Work-life balance measures for persons of working age with dependent relatives in Europe - A Study of National Policies*, Brussels: European Commission, Brussels, 2016.

18) D. Bouget, S. Spasova and B. Vanhercke, *Work-life balance measures for persons of working age with dependent relatives in Europe - A Study of National Policies*, Brussels: European Commission, Brussels, 2016.

19) Ibid, pp. 18.

2. LEAVES, CASH BENEFITS AND BENEFITS IN-KIND FOR CARERS IN THE EUROPEAN LONG-TERM CARE SYSTEMS

Carers' support in different long-term care systems varies in relation to scope, types and emphasis of provision. While some countries place greater accent on care services, others have prioritized financial benefits as a means of facilitating carers' private and professional life. Four analysed countries below, belonging to different long-term care "regimes", provide insight into diversity and prominence of carers provision in Europe.

Sweden has been placed into the first broad category – developed and mature support schemes for carers, within the Bouget, Spasova and Vanhercke (2016) categorisation of long-term care regimes, characterised by specific arrangements targeted at carers, and/or provisions granted to the dependent person who uses them to pay a carer. In addition, Sweden belongs to the first subgroup of countries from the first broad category, considered to have relatively universal and comprehensive LTC support scheme, with well-established, long-lasting tradition of LTC, regardless of the age of the dependent person, and where organising such care is seen as a public responsibility. Individual independence is a key feature of these policies, and there is no legal maintenance obligation between relatives. According to Bouget, Spasova and Vanhercke²⁰⁾ there are three main features of this system: a) mix between mostly short-term leaves, cash benefits and benefits in kind specifically targeted at the carer, and those geared to the dependant, as well as a broad supply of respite support (a short break from caring duties); b) widespread, well-developed and accessible in-home services (medical assistance, household services), which reduces the need for care provided informally; and c) generous LTC provisions in kind (both to the dependent person and to the carers). All these, together with the flexible structure of the labour market, often allow the carer to stay in employment during care obligations. Hence, the consequence on the carer's well being is rather positive. In terms of goals and principles of the LTC, the main responsibility lies with the national government, while municipalities are in charge for funding and service/benefits provision. The principle of universalism in Sweden was challenged during the 90ties, due to the economic recession, which resulted in: reduc-

20) D. Bouget, S. Spasova and B. Vanhercke, *Work-life balance measures for persons of working age with dependent relatives in Europe - A Study of National Policies*, Brussels: European Commission, Brussels, 2016.

tion of public long-term care provision, support towards the consumer choice models, and focus of the care on the neediest.

Germany belongs to the same broad category of developed and mature support schemes for carers as Sweden, but to a different subgroup of countries providing provisions mainly to the dependent person and specific support to the carer.²¹⁾ According to Bäcker²²⁾, Germany's LTC system can be considered to have the following characteristics: a) It is targeted at support for the carer (usually relatives); b) Provides generous leave conditions and specific cash benefits targeted at the cared-for person, who uses them to buy in care; c) Well-developed Institutional care (residential care, day care provided in institutions, etc.); d) Benefits in kind, mainly granted to the cared-for person, but considered as an important indirect support to the carer; and e) Benefits that are targeted at the dependent person but specifically provide support to the carer, most often a family member. Following the Bismarckian tradition, Germany introduced a LTC insurance scheme in the 1990s, as the fifth pillar of the national statutory insurance system, with benefits based on insurance claims. LTCI distinguishes between three levels of care and three different arrangements. A recipient can choose from: care allowance, home care (in kind) and residential care. Taking into consideration main principles of long-term care provision, it may be argued that overall contours of the German LTC system coincide with the Esping Andersen welfare state description. It is insurance based, contributory based, with the social market economy approach. Also, long-term care insurance principle follows the health insurance logic and covers almost the entire population (around 90%).

UK is a specific case related to carers support as part of the long-term care system. Namely, in different regimes, it is placed differently depending on the variables chosen. For example, in Schulmann and Leichsenring²³⁾ it is defined as a "standard-care mix" regime, with medium/high demand for care, medium/low provision of informal care and medium provision of formal care. In Kraus et al.²⁴⁾ England (as representative of UK) is part of the cluster whose nature of the system is defined as informal and care oriented, with following characteris-

21) Ibid.

22) G. Bäcker G, *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives – Germany*, European Commission, Brussels, 2016.

23) K. Schulmann and K. Leichsenring, *Social support and long-term care in EU care regimes*, European Commission's Seventh Framework Programme FP7-SSH-2012-1/No 320333, 2014, Internet, www.mopact.group.shef.ac.uk, 05/04/2016

24) M. Kraus, T. Czipionka, M. Riedel, E. Mot and P. Willemé, *How European Nations Care For Their Elderly - A New Typology Of Long-Term Care*, Enepri Policy Brief, No. 7 July 2011.

tics: medium spending, high private financing, high informal care use, high informal care support and high cash benefits. Some of the reasons for different positioning of UK/England in relation to long term care regime clusters and particularly its focus on carers, lies in the difference between legislative provisions and their implementation. Namely, while there are specific leaves, cash benefits and benefits in kind provided to the carer, they are subject of strict eligibility conditions and/or dependent on negotiation with the employer. Main type of carers support in UK, includes: a) Flexible working and time off in emergencies; b) Carers Allowance and Carer Premium and c) Assessment of carers needs, respite breaks, one-off cash payments, service Information and advice, etc. As outlined by Glendinning²⁵⁾, the current long term care system in UK produces “high proportions of carers who give up paid work because of care responsibilities, very small proportions who combine any more than minimal care-giving with full-time work and the significant uncompensated earnings lost by those who reduce from full- to part-time work.”

Finally, *Italy* has been described as a “family based” long-term care regime by Schulmann and Leichsenring,²⁶⁾ where a “migrant-in-the-family” model of care has emerged. Regarding carers, there is a generous and developed care leave system (both short and long leave provisions), a universal flat rate benefit (*Indennità di accompagnamento*) and a limited provision of home and residential care services. The combination of these measures offers a degree of reconciliation between private and professional life of carers. However, as indicated by Jessoula, Pavolini and Strati²⁷⁾ “the weaknesses of the LTC system and of the measures taken to reconcile the work-life balance for people of working age with dependent relatives is linked to the provision of carer’s benefits in kind and LTC services”. According to them, it is increasingly difficult to reconcile working and caring, in a context of unchanged family organisation that has weakened the traditional intergenerational solidarity, on which the Italian LTC system was historically grounded.²⁸⁾ Despite the fact that the Italian LTC system has invested a significant amount of resources in fostering reconciliation between

25) C. Glendinning, *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives in UK*, European Commission, Brussels, 2016, p. 4.

26) K. Schulmann and K. Leichsenring, *Social support and long-term care in EU care regimes*, European Commission’s Seventh Framework Programme FP7-SSH-2012-1/No 320333, 2014, Internet, www.mopact.group.shef.ac.uk, 05/04/2016

27) M. Jessoula, E. Pavolini and F. Strati, *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives in UK*, European Commission, Brussels, 2016.

28) *Ibid*, p. 5.

family life and work still, according to EU Labour Force Survey data, Italian family caregivers are less capable than their western European counterparts to access flexible working times.

More direct comparison between carers' leaves, cash benefits, and benefits in kind shows that analysed countries differ in relation to emphasis on support mechanisms regarding carers. While Sweden's LTC system is characterised by generous benefits targeted both at the dependent person and the carer, with focus on social services provided by municipalities at local level, Germany's benefits are mostly designed to provide support to the carer, most often a family member, as there is strong emphasis on reconciliation of work and care obligations. Other differences that emerge show that, while in UK we see a well-developed system of carers' benefits in kind, in Italy this is the least developed and effective aspect of the LTC system. On the other hand, Italy has generous, universal and flat rate system regarding carers' leaves and cash benefits, while in UK this is conditional and means tested.

Also, analysed case studies show that their long-term care sectors correspond in general with the Esping Andersen's welfare states regimes. Some divergence may be seen in the case of Sweden. As rightly pointed by Karlsson, Iversen and Oien,²⁹⁾ the long-term care sector in Sweden shows "the difficulty of reconciling the Scandinavian welfare state universalism and political tradition of strong local autonomy". As they point out, greater universalism at the expense of local autonomy has been practised in a way that Swedish national government provide funds that the local authorities can apply for. In the other three countries, we see overlapping of LTC characteristics with the general welfare state model. Lack of more visible support towards carers in the case of Italy can be associated with the tradition of familialistic approach, where caring responsibilities lie within the family while the government modestly supports them. Greater possibilities for reconciliation between professional and private life of carers may be observed in Sweden and Germany, where focus on (non-negotiable and paid) leaves and in-kind benefits take pressure off from the caring duties.

The carers' perspective of long-term care shows these systems are path-dependent, and influenced from their welfare legacies and traditions. Despite recent reforms undertaken in the some of the countries, still analysed national LTC sectors does not significantly alter or change traditional welfare architectures. Taking into consideration European

29) M. Karlsson, T. Iversen and H. Oien, *Scandinavian Long-Term Care Financing*, Working Paper 2010:2, University of Oslo, Health Economics Research Programme, Oslo, 2010, Internet, http://www.med.uio.no/helsam/forskning/nettverk/hero/publikasjoner/skriftserie/2010/2010_2.pdf, 24/04/2016

demographic trends and anticipation of even greater demand for long-term care on one side, and labour market trends among carers on the other, it will be necessary for most of the LTC systems, particularly in those where there is a limited governmental role, to place more emphasis on support mechanisms which integrate caring duties and participation and remaining in the labour market.

3. MACEDONIA: LACK OF WORK-LIFE BALANCE MEASURES FOR CARERS WITH DEPENDENT RELATIVES³⁰⁾

The long-term care regime in Macedonia has not been part of the existing welfare state typologies, nor long-term care regimes. Classification provided by Bouget, Spasova and Vanhercke³¹⁾ places Macedonia in the cluster of countries with underdeveloped support schemes for carers. This is justified, as long-term care support in the country provides rights and services mainly to those being cared for. Carers' rights, especially leave and in-kind benefits, are not comprehensively developed. The regime was partly established under the previous socialist system (pre 1991), and the dominant form of support included residential care (which is now largely privatized) and cash benefits. In recent years, some new forms of cash benefits have been introduced. However, labour market support of carers is still marginalized, making carers more vulnerable in relation to employment and decent living standards.

Long-term care benefits are mainly provided to cared-for persons. There are only two long-term care benefits for carers, and eligibility for these two benefits is limited only to carers who are parents. There are no specific in-kind benefits that are provided to support people with dependent relatives. In-kind support is provided only to cared-for persons.

The coverage of the long-term care regime in relation to carers is very narrow, as it only concerns parents of disabled children. Hence, other categories of people – such as spouses and other family carers who are working and at the same time providing help and assistance to a family member in need of long-term care – are not covered or sup-

30) This part builds on the ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives in former Yugoslav Republic of Macedonia (2016), author: Gerovska Mitev, M.

31) D. Bouget, S. Spasova and B. Vanhercke, *Work-life balance measures for persons of working age with dependent relatives in Europe - A Study of National Policies*, Brussels: European Commission, Brussels, 2016, p. 9.

ported through social, health or employment measures. Take-up is also very low. Official statistical data for 2014 show that, in the case of the only social protection right/benefit aimed at carers, only 9.1% of all potential beneficiaries used it.

3.1. Overall description of long-term care regime

Long-term care is not ensured by a single system, but it is provided partly under the social protection and pension insurance system (run by the Ministry of Labour and Social Policy) and partly under the health care system (under the responsibility of the Ministry of Health). Each of these systems has its own legal regulations, criteria of accessibility and quality, and method of financing. Apart from the state-guaranteed systems, family members and other close persons traditionally provide long-term care. Long-term care is financed primarily from state funds, but also by the care recipient and/or their family.

In terms of overall support, the long-term care regime in the Macedonia consists of combinations of rights related to: (i) financial support; (ii) residential and non-residential services; and (iii) carers' leave. In addition, informal care-giving is a substantial part of caring for dependent people.

Institutionalized forms of long-term care are provided through social and health care institutions, as well as through some home-based services provided at community level. Institutional protection for old people is insufficiently developed compared with some European states. This can be illustrated by the fact that only four public homes for old people are in existence. Non-institutional protection is provided under the health and social protection system through a number of services that are insufficiently developed and coordinated. There have been very small steps in the direction of de-institutionalizing services for people with disabilities within the social protection system, but they are not yet sufficient.³²⁾

The scope of rights related to long-term care is specified in the laws on health protection, health insurance, social protection and labour. The existing legal provisions cover the long-term care protection of elderly persons, as well as of children and persons with physical, mental and/or developmental disabilities.

1.2. Description of carers' leave

As previously indicated, the least developed aspect of the long-term care regime in Macedonia is the support for carers' leave. There

32) V. Dimitrievska, "The Model of Long-Term Care in R. Macedonia", *Journal of Social Policy*, Year 3, No. 5, 2010, pp. 468–484.

is only one scheme that enables shortened working hours (which is not strictly a form of leave). Also, eligibility for this scheme is very narrowly defined and can be used only by parents (not relatives or other family members).

The only leave scheme concerns parents caring for children with developmental problems and special educational needs, under the Labour Law (art. 169).³³⁾ One of the parents (or a single parent) has the right to work part-time, subject to approval by a medical commission (if the child is not in residential care). According to the rulebook for acquiring this right (Official Gazette No. 49/2013), applicants need to provide a decision from their employer supporting their use of the right to shortened working hours according to the law. The shortened working hours, under this article, are treated as full-time working hours, and the right to salary compensation is regulated according to the Law for Social Protection (described later in the section on carers' benefits).

The other option that carers may use is unpaid leave (art. 147 of the Labour Law), which may be taken for up to a maximum of 3 months during one calendar year. This right is administered through employers, who send a form to the Employment Agency confirming the suspension of the employment contract due to the use of the right to unpaid leave. The criteria and conditions for using this right are regulated under collective agreements.

3.3. Description of carers' cash benefits

Long-term care benefits are mainly provided to dependent persons. There are only two long-term care benefits for carers, and eligibility for these two benefits is limited to carers who are parents.

Salary compensation for shortened working hours due to care of a child with developmental problems and special educational needs: this is currently the only benefit paid directly to carers, i.e. the parents. It is paid at a fixed amount of 4,987 Denars (EUR 81), which represents 52% of the minimum wage. Salary compensation is financed from the state budget. The part-time working hours are treated as full working hours.

Financial assistance granted to a single parent with a disabled child, upon reaching pensionable age: this is a newly established right (in 2014). It is paid to a single parent who takes care of their disabled child until the child reaches the age of 26 (continuously for 15 years) provided that the parent is unemployed or not entitled to a pension. The benefit is given to the single parent upon reaching pensionable age,

33) Labour Law, Official Gazette of the RM, No. 167.

i.e. 62 (women) or 64 (men). The benefit represents a form of pension, paid as a fixed monthly payment set at 8,000 denars (EUR 130), which represents 83% of the minimum wage.

The main beneficiaries of other benefits are dependent persons. These include: 1) Financial reimbursement for assistance and care (amounting either 62 or 70 Euro per month); 2) Special allowance for disabled children up to 26 years of age (71 Euro per month), 3) Permanent financial assistance (means tested, 60 Euro for a single beneficiary); 4) Allowance for mobility (114 Euro per month); Allowance for blindness (114 Euro per month) and Allowance for deafness (65 Euro per month).

According to data from the State Statistical Office for 2014, out of all the above-mentioned rights, the most used was financial reimbursement for assistance and care, while the least used was the salary compensation for shortened working hours.

3.4. Description of carers' benefits in kind

In Macedonia there are no specific in-kind benefits that are provided to support people with dependent relatives. For dependent persons, there is homecare and assistance – mainly for elderly and disabled people.

Institutional care for disabled and elderly is very limited. Data from the World Health Organization and Public Health Institute indicate that “In 2013, the total available beds from care units and private homes for elderly was 930 beds, or 44.8 beds per 100.000 inhabitants”³⁴⁾. Limited provision is not the only concern, but also the affordability of the accommodation as majority of them (534 beds) were provided by private homes for elderly.

The social protection system offers access to day care centres, small group homes and accommodation in a foster family. Day care centres for disabled people, run by the state or non-governmental organizations (NGOs), provide a stay on a day or half-day basis, nutrition and personal hygiene, as well as working, cultural, entertainment and other activities. Institutionalized care is still a dominant form of social care, while other forms of non-residential care are less utilized.

The health care system offers specialized day care centres and centres for palliative care, community mental health centres that provide services through, sheltered homes, social clubs, and mobile teams that provide home treatment. The main beneficiaries of these services are dependent persons.

34) ESE, *The cost of unpaid care for dependent adults*, Association for Emancipation, Solidarity and Equality of Women - ESE, Skopje, 2016, p. 5.

In addition, pensioners in need of long-term care are entitled to rehabilitation and spa treatments on the basis of an established diagnosis and referral issued by their personal doctor and a medical committee.

3.5. Effectiveness of work-life balance measures for working-age people with dependent relatives

As can be seen, the formal support given to the carers of dependent children and relatives is very limited. The *coverage* is also very narrow, as it only concerns parents, who in turn are provided with very few support measures – shortened working hours, salary compensation for shortened working hours, and financial assistance (not yet accessible) to a single parent with a disabled child, upon reaching pensionable age. Hence, other categories of people – such as spouses and other family carers who are working and at the same time providing help and assistance to a family member in need of long-term care – are not covered or supported through social, health or employment measures. According to the State Statistical Office data, there is a very limited take-up of the benefit - salary compensation. In 2014 only 9.1% of the 715 employees who were working shortened hours, used the benefit.

The overwhelming majority of family carers are women.³⁵⁾ Taking into consideration considerable degree of undeclared work in the country, it may be said that there is a large number of women who do not participate in the labor market due to care for dependent persons in the family.

Carers from more vulnerable ethnic communities, such as Roma are even more affected, as they face highest rate of unemployment and poverty in the country. According to a recent research, based on interviews with working age carers from 19 Roma households, majority of them were unemployed women, not looking for job due to caring duties. Average time they spend on caring duties is around 37 hours a week, or 22% of their time during the day.³⁶⁾

The limited provision of support for carers makes it impossible to reach any conclusions as to their employment effects. In general terms, combining the benefits given to the cared for and benefit for carers, contributes to some extent towards offsetting the financial costs of the carers. Overall, carers are faced with continuous challenge of: providing financial resources for individual and the cared-for needs;

35) State Statistical Office, *Labour Force Survey 2015, 2014, 2013, 2012*, State Statistical Office, Skopje.

36) ESE, *The cost of unpaid care for dependent adults*, Association for Emancipation, Solidarity and Equality of Women - ESE, Skopje, 2016.

exclusion from the labor market, lack of sufficient support of combining shortened working hours and caring duties, lack of social security in the old age.

It can be concluded that the overall package of measures aimed at carers and the cared-for is not balanced. Almost all measures are aimed at dependent people, with a clear lack of specific support for carers such as longer leaves and in-kind benefits. The only aspect that provides some support to carers and the cared-for is the financial benefits from the social protection system. The possibility of combining these can in many cases lead to an income close to the national average salary, but it certainly does not contribute to work-life balance for carers.

Taking into consideration all of the above, reform of the long-term care system is an urgent issue.

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**ИДЕОЛОГИЈЕ ДРЖАВНОГ БЛАГОСТАЊА И
РЕЖИМИ ДУГОРОЧНЕ НЕГЕ:
ИЗАЗОВИ НЕГОВАТЕЉА У МАКЕДОНИЈИ**

Резиме

Анализа система дугорочне неге у развијенијим европским државама благостања показује да се не посвећује подједнака пажња улози приватног и професионалног живота. Такав баланс је више остварив кроз различите исплате послодаваца и сервисе у Шведској, као и кроз различита социјална давања и систем социјалне заштите у Немачкој. Остале земље захтевају доказе за обезбеђена права (Уједињено Краљевство), а пружају и ограничене јавне сервисе (Италија). То показује да се неговатељи сусрећу са различитим изазовима зависно од режима или система социјалне заштите. Неговатељи у Шведској имају обезбеђен интегрални пакет примања и социјалних сервиса, али то може водити „родној замци“. Коришћење неговатељских примања може навести да само жене обављају неговатељске улоге и доведу у питање остварен висок ниво запослености у овој земљи. Систем социјалне заштите у Немачкој може бити од користи неговатељима са пуном и стабилном зарадом, али и ризичан за незапослене неговатеље или оне са мигрантском прошлошћу. Неговатељи у Уједињеном Краљевству у великој мери зависе од послодавца, док италијанским неговатељима недостаје најважнија подршка, тј. више доступних социјалних сервиса и размена. Такође, подршка неговатеља у анализираним европским режимима дуготрајне неге може се повезати са традицијом и идеологијом благостања у оквиру које је настала и касније реформисана. Такав развојни пут је у извесној мери тежак за остваривање у светлу демографских тенденција и показатеља тржишта рада у Европи. Пример система социјалне заштите у Македонији потврђује случај мање развијене и нестабилне државе благостања. Упркос чињеници да актуелни систем социјалне заштите потиче из ранијих социјалистичких времена, он је још увек фокусиран на бригу за особе. Породична брига се помаже само симболички, и то укључује само неговатеље који су родитељи. Остали типови породичне неге нису покривени никаквим типом примања, социјалних сервиса или размене. То представља велику препреку за неговатеље, који су иначе погођени неповољним социјално-економским

показатељима високе незапослености (24,5% у првој четвртини 2016. године) и ниске просечне месечне разраде (360 евра). У најтежем положају су незапослени неговатељи, неговатељи из мањих етничких заједница (попут Рома) и, посебно, жене из таквих домаћинстава. Стога је потребно хитно спровести реформу, али то се, нажалост, још не види на политичком дневном реду.

Кључне речи: држава благостања, дугорочна нега, зависност, неговатељи, давања, социјална примања, исплате послодаваца.

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