

ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives

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Highlights

In Bulgaria, long-term care (LTC) services are provided by two different systems: the healthcare system and the system for provision of social services.

LTC services are provided by the healthcare system in different kinds of specialized medical institutions, such as: hospitals for long-term and continuous treatment, rehabilitation hospitals, state psychiatric hospitals, centres for mental health, and hospices. The provision of social services for LTC is regulated by the Social Assistance Act and a related by-law. Social services in Bulgaria can be financed through: the state budget (as state-delegated activities); municipal budgets (as local activities); various projects under national and international programmes; or self-financing, where services are provided by registered private providers.

In general, in Bulgaria, there is a variety of care institutions and programmes concerning the provision of LTC services, regulated by many different laws. They do not operate under a rationalized, well-organized and institutionalized body. The services provided by those institutions are of limited coverage and insufficient quality, and are inadequate to meet the rising needs and demands for such services. This places a big share of financial and practical responsibility on the family. There are many political and legislative changes that have taken place recently in this area, but there is a lack of scientific data on the results, and of studies designed to follow up and validate the changes.

Medical sickness certificates provide access to care for an ill family member at home, and for the care of a child placed with relatives or a foster family. The certificate can be prescribed by a doctor, a dentist, a Medical Advisory Committee or a Territorial Expert Medical Commission.

The circle of relatives who have the right to leave work and the right to financial compensation for caring for a sick family member includes ascending and descending lineal relatives of the sick person and their spouse.

The sick-leave schemes available in Bulgaria in the context of LTC, and the cash benefits designated for people in need of long-term care, do not create disincentives regarding gainful employment. The wage-replacement rate of care-leave benefit is quite high (80%), but opportunities for temporary leave from work are only available for rather short periods of time. Sick-leave schemes only provide some support for a limited time for people who have to organize new arrangements for relatives needing LTC.

The coverage of services for the elderly remains insignificant compared with demand, and their quality also needs significant improvement. However, there are currently many proposals on the political agenda in Bulgaria, together with on-going reforms in the health and social areas that will affect work-life balance for carers, as well as the well-being of carers and their family members, in the very near future.

Financial and organizational sustainability need to be ensured for the application of LTC policies, and for LTC services developed in the community that currently rely on temporary financial sources. There is also a real need for in-depth studies and analyses of the employment effects for carers, and of the overall effects of the existing LTC regime on the well-being of informal carers and the cared-for, in order to provide an evidence base for continuation of the reforms.

1 Description of main features of work-life balance measures for working-age people with dependent relatives

1.1 Overall description of long-term care regime

In Bulgarian research focused on the topic of work-life balance, care for two types of dependent persons is discussed – the raising of children, and the care of elderly/sick/disabled family members (Kovacheva, 2010). The issue was first addressed in the years just before Bulgaria joined the European Union (EU). Another topic is the unequal division of household tasks and unpaid care work. In Bulgaria, there is little expectation that fathers should play an active role in parenting. There is also no legal provision explicitly supporting parents, which is the reason why they usually rely on informal support from line managers, colleagues, relatives and public nurseries (Kovacheva, 2009). More recent overviews of existing policies on work-life balance have confirmed the conclusion that at company level there are no established practices aimed at supporting parenting (Kotseva, 2013).

An empirical survey was carried out when Bulgaria joined the EU to find out which types of contract and which types of organization were most beneficial to flexible and non-stressful work-life arrangements. This survey was conducted some time ago: but nonetheless we believe it is still highly relevant. It discovered that significant differences existed between companies operating in different sectors of the economy – with the financial institutions being least favourably inclined towards people who needed to care for dependants (Kovacheva, 2009). During the first decade of the 21st century, part-time work was not widely available in Bulgaria compared with other EU member states (Lewis, Brannen, Nilsen, 2009). In this respect, there has been no change during the second decade.

In Bulgaria, there is a variety of care institutions and programmes concerning the provision of LTC services, regulated by many different laws. They do not operate under a rationalized, well-organized and institutionalized body. The services provided by these institutions are of limited coverage and insufficient quality, and are inadequate to meet the rising needs and demands for such services. This places a big share of financial and practical responsibility on the family.

In Bulgaria, at government level, LTC services are provided by two different systems: the healthcare system and the system for provision of social services. The key institution for long-term care within the healthcare system is the hospice. Hospices in Bulgaria are registered under the general regulations for healthcare establishments.

Table. Number of hospices and number of beds in hospices in the period 2007-2014

Establis hments	2007		2008		2009		2010		2011		2012		2013		2014	
	Nu mbe r	Bed s														
Hospices	39	398	49	418	59	659	54	716	49	790	41	802	45	867	45	959

The number of available beds in hospices has been growing steadily since 2007. It almost tripled in seven years, while the number of establishments remained almost unchanged, which means that hospices have become bigger.

LTC services provided by the healthcare system in different kinds of specialized medical institutions – such as hospitals for long-term and continuous treatment, rehabilitation hospitals, state psychiatric hospitals, centres for mental health, and hospices – are regulated by the Law on Health and the Law on Medical Establishments. The financing of most of those institutions is through the National Health Insurance Fund via clinical pathways and they are free for health-insured persons. Only state psychiatric hospitals

and centres for mental health are financed through the Ministry of Health budget (they are also free for all citizens).

The provision of social services for LTC is regulated by the Social Assistance Act and a related by-law. Social services in Bulgaria can be financed through: the state budget (as state-delegated activities); municipal budgets (as local activities); various projects under national and international programmes; or self-financing, where services are provided by registered private providers.

Social services in the community are provided through personal assistants, social assistants, home assistants, home care, day care centres for children and/or adults with disabilities, day centres for elderly people, and centres for social rehabilitation and integration.

Residential social services provided in Bulgaria include: family-type centres or homes for children/young people without disabilities; family-type centres for children/young people with disabilities; family-type centres or homes for adults with mental disorders or dementia; family-type centres for adults with physical disabilities; family-type centres for adults with mental disability; and family-type accommodation for the elderly and others¹. There are six types of residential institution for elderly people, with a total capacity of about 11,500 places. The most widespread type is the so-called Homes for Elderly Persons, which are not specialized and account for about half of the available places. The other five types specialize in hosting elderly people with specific mental or physical disabilities. A National Concept Paper published by the government in 2012 also enumerated nine types of existing community-based services, such as day-care centres, shelters, and mid-houses, with a total capacity of 6,893 places².

Social services in specialized institutions are provided after the opportunities for community services have been exhausted. There are several types of service that are relevant to work-life balance, though many of them do not have an exclusive focus on it.

There are, first, several centres that provide day services or **temporary accommodation**: a) centres for temporary accommodation, b) crisis centres, and c) transitional housing.

Some services provide **longer-term accommodation** in the form of protected homes ³: a) sheltered homes for people with mental disorders, b) sheltered homes for people with mental disability, c) sheltered homes for people with physical disabilities, d) supervised housing, e) shelters, and f) public canteens. Specialized institutions for providing social services related to long-term care are ⁴: a) homes for adults with disabilities, b) homes for adults with mental disorders, d) homes for adults with physical disabilities, e) homes for adults with sensory disorders, f) homes for elderly people with dementia, and g) old people's homes.

In addition, some cash benefits and allowances for people with disabilities are specified in the Labour Code and the Law for Integration of People with Disabilities. In 2015, the government undertook a number of legislative changes in the field of social services. Changes in the Health Act are aimed at improving the government of integrated health/social services. The Council of Ministers sent to the National Assembly an amendment of the Social Assistance Act. Development of a law on social services, aimed at improving the system of financing, quality, effectiveness, and control, etc., has been going on for two years. The main reason for the extended timescale is the need for further studies and discussions to reflect all opinions and trends in the field. With the changes in the Law on Medical Establishments, a new type of medical establishment has

¹ Regulations for implementing the Social Assistance Act, Art.36, 2014.

 $^{^2}$ Национална концепция за насърчаване на активното стареене на възрастните хора в България (2012-2030) National Concept Paper for Stimulating Active Ageing of the Elderly Persons in Bulgaria (2012-2030), 2012.

³ (amend. - SG. 55 of 2014, effective 1.01.2015).

⁴ (amend. - SG. 31 of 2005 pcs. 103 of 2005 pcs. 101 of 2007).

been created, specialized in providing care to **children with disabilities and chronic diseases**. This reform is likely to have a positive impact on the overall well-being of children with disabilities and chronic disease and the access of their families to services⁵.

Another reform in the healthcare field that is likely to have a positive impact on access to long-term healthcare is the introduction of a mandatory National Healthcare Map. This mainly covers the transformation of hospital beds from acute to long-term care. More than 530,000 bed days are planned to be financed for this year within the three new clinical pathways for prolonged treatment.

The National Long-term Care Strategy⁶ aims to provide the conditions, over the next 20 years, for improvinge access to social services in the community and family environment, as well as to health services. It will do this by expanding the network of these services; improving their diversity, volume and scope; enhancing their quality; and encouraging interaction between social and healthcare⁷. Deinstitutionalization was presented in the National Long-term Care Strategy as a main target for long-term care reform. Deinstitutionalization means closing down institutions and reducing the capacity of residential care but, at the same time, opening new places in non-residential care and increasing the capacity of community-based services. This process was already under way and continued in the years after the strategy was approved, but it was not very rapid. The population will continue to grow older due to low birth rates, emigration of younger generations and increased life expectancy. Increased old-age dependency ratios make it difficult to organize long-term care in a family environment. The strategy calls this type of care informal care as opposed to the formal care provided by specialized professional organizations. In the 21st century the share of informal care has been growing: but the existence of fewer younger and healthier family members will make it less likely to find people who are available to deliver care services. The total number of social service institutions for the elderly and people with disabilities was 572 at the end of 2013, with capacity for 19,489 people. Deinstitutionalization might put additional pressure on family and carers, and worsen their work-life balance.

Successful social services to support families in caring for dependent family members include 'personal assistants', 'social assistants" and 'home assistants'. Social services personal assistants and social assistants are provided under the 2003 National Programme 'Assistants for People with Disabilities', which covers care in a family environment to people with disabilities or seriously ill people, by recruiting unemployed people as personal or social assistants (the social assistant, unlike the personal assistant, is not a member of the family). Within the Operational Programme 'Development of Human Resources' 2007-2013, a number of schemes were implemented that were aimed at ensuring provision to meet a growing need for quality care in a home environment, and to test and implement new approaches to care for the most vulnerable people. Relevant examples are the project 'Support for a decent life', the 'Alternatives' programme, projects under the 'Help at Home' programme, 'Home Care for independent and dignified life' programme, and others8. Centres and units for services at home will be established under the 'Help at Home' programme.. They will provide care on an hourly basis for the disabled and elderly to overcome the difficulties that they have with existing service. This new scheme will take over servicing of around 14-15,000 people.

⁵ Announced on 12 February, 2016 by the Minister of Health Dr. Petar Moskov at a special meeting with mayors, governors, heads and directors of hospitals in Gabrovo.

⁶ Национална стратегия за дългосрочна грижа (National Long-term Care Strategy), Министерство на труда и социална политика, 2013. National Strategy for Long Term Care, Ministry of labour and social policy, 2013

⁷ National Strategy for Long Term Care, adopted by Decision № 2 of the Council of Ministers on 07.01.2014, http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG&Id=882

European program gives 20 million Bulgarian levs to the people with disability, BTV 30.01.2016 http://m.btvnovinite.bg/video/bulgaria/obshtestvo/evroprograma-predostavja-20-mln-leva-za-horata-s-uvrezhdanija.html

In the context of the Europe 2020 strategy, Bulgaria adopted a national goal of 'reducing the number of people living in poverty by 260,000 people by 2020'. A sub-goal of the national goal is to reduce the number of people aged 65 and older living in poverty. One of the key measures under this sub-goal is the creation of a network of services for long-term care. Achieving this will contribute to a more dignified and fulfilling way of life for older people and people with disabilities. At the end of 2015, an analysis of specialized institutions was developed that will support reform in the field of deinstitutionalization of care for people with disabilities and the elderly. At the end of October 2015, 474 social service institutions for the elderly and people with disabilities operated in the community, 44 more than at the end of October 2014, with the number of people benefiting from them increasing by 629. To provide more opportunities for older people, and those who care for them, two new schemes will be implemented – 'New Alternatives' and 'Independent Living'. The indicator for the share of the population aged 65+ at risk of poverty shows improvement; in 2014 it decreased by 5.3% compared with 2013°.

The political will to improve the adequacy of LTC for disabled people is demonstrated by the intention on the part of the Ministry of Health and the Ministry of Labour and Social Policy to produce major reforms in the assessment and recognition of disability. The declared aim is to stop abuses and the draining of public funds, and to improve the current cumbersome system for proof of disability. The identified measures are designed to allow people with disabilities to receive quality medical expertise without delay, and to help those who can work to swiftly rejoin the labour market in their previous job with the help of active assistance from the state.. A new methodology will be used to assess the residual functionality of people with disabilities. Two new committees will replace the existing Medical Advisory Committee (MAC) and TEMC (Territorial Expert Medical Commission). The first committee will have medical expertise and will be affiliated to the Ministry of Health. It will follow the World Health Organization (WHO) model and will assess the residual functionality of disabled people. The second committee will be able to evaluate the decision of the first committee and make individual recommendations regarding a particular person with a disability; what type of job they could do, scope for further education, etc. The social committee will include representatives of several institutions - a doctor, an insurer, and an expert in occupational medicine. The element of corruption is expected to be minimized.

Children and disabled pensioners will, after medical assessment, be sent automatically to the social committee¹⁰. People of working age, however, will go through an assessment of performance. The options envisaged for these persons should enable either a return to the same job where they worked before with reduced performance, or the possibility of further education or rehabilitation through the facilities of the Institute¹¹.

On September 9, 2015 the National Assembly adopted the changes in the Law on Medical Establishments. The National Healthcare Map was made mandatory. New procedures for the creation of district healthcare maps were defined in the law. The aim

⁹ Доклад за напредъка в изпълнението на мерките в Националната програма за реформи за 2015 г. май-октомври 2015 г., Декември 2015 г., Министерство на финансите, дирекция "Икономическа и финансова политика" България. Progress report on the implementation of the measures in the National Reform Programme for 2015 from May to October 2015, December 2015, Ministry of Finance, the 'Economic and Financial Policy' Bulgaria.

¹⁰ According the Health Act.

¹¹ Minister Kalfin introduced reform in the commotions at front of members of the parliament, Investor.bg, 30.02.2016 http://www.investor.bg/ikonomika-i-politika/332/a/kalfin-predstavi-proekta-za-reforma-na-telk-ovete-pred-deputatite-210670/

is to stop the unnecessary proliferation of hospitals and make the distribution of medical resources across Bulgaria more balanced 12.

In general, in Bulgaria, there is a variety of care institutions and programmes concerning the provision of LTC services, regulated by many different laws. They are not operating under a rationalized, well-organized and institutionalized body. The services provided by those institutions are of limited coverage and insufficient quality, and are inadequate to meet the rising needs and demands for such services. This places a big share of financial and practical responsibility on the family. There are many political and legislative changes that are taking place recently in this area, but there is a lack of scientific data and of studies designed to follow up and validate the results of those changes.

1.2 Description of carers' leave

1.2.1 Maximum duration of such leave

The law provides an opportunity for people to take leave from work to take care of a sick family member¹³.

Every insured person is entitled to 10 days of paid leave per calendar year to provide care to sick family members over the age of 18, or to accompany them for medical examination, investigation or treatment either in the country or abroad. Those who provide the same care for family members under the age of 18 are entitled to up to 60 days in one calendar year.

In addition, people may use unpaid leave for the same purpose, but this is subject to employer approval. Periods of up to 30 days of unpaid leave per year do not affect entitlement to old age pension.

Official regulations set different terms and conditions in relation to granting sick leave for the care of an ill family member at home compared with hospital inpatient care.

A medical sickness certificate regarding care for a sick family member in hospital is issued by the doctor after the head of the hospital has agreed that care for the patient is necessary for a specified period. The certificate is granted provided that, at the place where the patient resides, there is no other unemployed family member able to care for or accompany the patient. This is established through a declaration by the insured person to whom the certificate 14 is issued.

A medical sickness certificate allows for the care of an ill family member at home, and care of a child placed with relatives or foster family¹⁵, under Art. 26 of the Law on Child Protection (LOC).

The medical sickness certificate can be issued by:

- A doctor (or a dentist) 14 days continuously for one or more diseases.
- A Medical Advisory Committee up to 30 days at a time, but not more than 6 months.
- A Territorial Expert Medical Commission after 180 uninterrupted days, or 12 months with a break, in the two previous years of illness.

For care of a chronically ill family member, a medical sickness certificate is issued and monetary compensation is paid only when: a new disease is added that

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¹³ Art. 162 of the Labour Code in conjuction with art. 45 of the Social Security Code.

¹⁴ Art. 162 of the Labour Code, Art. 45 of the Social Security Code and Art. 37 and 39 of the Ordinance on the medical expertise of disability.

¹⁵ Art. 26 of the Law on Child Protection (LOC).

aggravates the condition and needs care; there is an exacerbation of the existing disease; or the disease reaches a terminal stage.

1.2.2 Payment level

The daily cash benefit based on a medical sickness certificate for caring for a sick family member is estimated at 80% of the average gross salary, or of the average insurance income used as a basis for the calculation of insurance contributions. Self-employed people receive a benefit that is calculated on the basis of insurance contributions for sickness and maternity leave for the period of 18 calendar months preceding the month of onset.

1.2.3 Eligibility conditions

The circle of relatives who have the right to take leave from work, and the right to financial compensation for caring for a sick family member, includes ascending and descending lineal relatives of the sick person and their spouse. The right to have a personal assistant applies to:

- people with at least 90% permanent disability;
- children with at least 50% reduced capacity for social adaptation;
- people or children taken from specialized institutions for people with disabilities.

1.3 Description of carers' cash benefits

In Bulgaria, there is no remuneration system for informal services provided by family members.

Monthly-based financial social assistance can be claimed by someone caring for a seriously ill family member. People are entitled to a monthly allowance if they either live alone or are in a family whose income for the previous month is lower than the differentiated minimum income. This applies to carers acting as either personal assistants (relatives) or social assistants (professional employees). The right to disability pension is awarded when the person has at least 50% reduced working capacity. Pensioners with a degree of disability over 90%, who need constant help, receive an additional pension allowance of 75% of the social pension for old age.

Monthly benefits for the care of a disabled child are payable regardless of family income. Each year, the Ministry of Labour and Social Policy determines the amount of aid for raising a child with disabilities. In 2014 the monthly allowance for raising a child until the age of two years was 100 BGN per month; the monthly assistance for a student with a disability, for the completion of secondary education, subject to not being more than 20 years of age, was 70 BGN per month.

State-supported community-based services for carers, such as respite support, training, and counselling are very limited. Some respite support for carers is obtainable from private service providers, if the family can afford it financially.

Due to lack of funds there has been a temporary suspension of the remuneration system that applied to carers acting as personal assistants (relatives) and social assistants (professional employees), providing care to lonely old people and the disabled (people with over 71% proven permanent disability). Social assistants who provide support with cleaning, personal hygiene, shopping and other everyday tasks are now provided by private companies at different prices depending on the region, combination of services etc.

1.4 Description of carers' benefits in kind

Disabled persons with over 90% of disability who have the right to assistance with daily living have the following additional rights for the assistant:

reduced price of public transport for their escort;

- two free trips by rail;
- targeted assistance for an assistant (escort) if they are impaired;
- periods of care count towards pension entitlement for the carer.

2 Analysis of the effectiveness of work-life balance measures for working-age people with dependent relatives

2.1 Assessment of individual measures

Bulgarian law does not have adequate provisions to ensure that people who have a sick family member can combine care for them with their professional duties.

The sick-leave schemes available in Bulgaria in the context of LTC, and the cash benefits designated for people in need of long-term care, do not create disincentives regarding gainful employment. The wage-replacement rate of care-leave benefit is quite high (80%), but opportunities for temporary leave from work are only available for rather short periods of time. Sick-leave schemes only provide some support for a limited time for people who have to organize new arrangements for relatives needing LTC.

A medical sickness certificate is only accessible for jobholders in dependent employment, but not for the self-employed or people with so-called freelance contracts.

Care for elderly and sick family members is an important reason for taking unpaid sick leave among women. In 2015, only about 13,000 men took leave in order to care for a sick family member, compared with 133,000 women¹⁶. This is one of the factors having a negative impact on women's careers and on the size of their pensions. In Bulgaria, specific support for home-based care only covers a very low proportion of related expenses and does not cover lost income due to provision of care. On the other hand, provision of care outside the family is also difficult due to shortages of qualified nursing staff. Bulgaria has experienced very large emigration of nurses and some other related professionals.

The work-life balance of people with relatives needing long-term care depends on many additional conditions, such as the accessibility and affordability of formal care services and the existence or otherwise of flexible working arrangements.

In Bulgaria, there have been no recent in-depth studies or analyses of the employment effects for carers of people with dependent relatives, or of the overall effects of the existing LTC regime on the well-being of informal carers and the cared-for.

An empirical study from 2014 focused mainly on the psychological aspects of the balance between work and life, and highlighted the importance of interpersonal relations for reducing stress, both in the family and at work. The study found that the presence of 1-2 children put more pressure on balancing work and family duties. Paradoxically, the study found that a third child did not produce more pressure, but instead the opposite (Andreev, 2014). We believe this is due to the fact that most of the families with three children or more have very low work intensity, and live in poverty and material deprivation. They are detached from the labour market, so that the issue of balancing tasks at work is not relevant to their situation. A study by the Bulgarian Academy of Sciences has shown that there is a statistically significant negative impact on health resulting from conflicting tasks in work and family life (Nedeva-Atanasova 2013).

According to the 3rd European Quality of Life Survey, the perceived quality of long-term care services in Bulgaria was the lowest of all 27 countries¹⁷.

¹⁶ Indicators for temporary inability to work, National Social Security Institute, 2015.

¹⁷ 3rd European Quality of Life Survey Quality of life in Europe, 2013: Quality of society and public services

http://www.eurofound.europa.eu/sites/default/files/ef_publication/field_ef_document/ef1361en.pdf

2.2 Assessment of overall package of measures and interactions between measures

The coverage of services for the elderly remains insignificant compared with demand, and their quality also needs significant improvement. The National Reform Programme (2015) mentioned a total of 542 service institutions for the elderly across the country covering 18,707 persons. But even this latter figure represented a negligible proportion of the elderly population. If Bulgaria wants to keep pace with the ageing of its population and resolve the scarcity of good-quality social services for the elderly, even for the current population, it needs to establish new services at a substantially faster pace. Within the framework of the current plans it is not clear how this can be achieved, but there are several policy and legislative measures in this area.

As services for long-term care in Bulgaria are provided by two separate systems - the system for social services and the healthcare system - deficiencies in social service provision put pressure on hospitals, which are often pressed to keep elderly patients for longer periods for social, rather than medical, reasons. This compensatory mechanism turns out to be very expensive. Previous attempts and plans to restructure the national system of hospital care failed to capture the depth of the problem, i.e. the insufficient capacity for long-term care and its impact on hospital care and healthcare expenditure. It was believed that long-term care services should be organized at municipal level due to differences in conditions between municipalities: but there was a failure to recognize that the large investments required for the establishment of such a system cannot be made by more than a handful of the biggest and richest municipalities. This means that a national policy, backed up by the necessary resources, is required in order to make such a system functional.

The new wave of restructuring of medical establishments that is under way, with the introduction of the new National Healthcare Map, is aimed at transforming inefficiently used acute care hospitals (or hospital beds) into long-care facilities with fewer medical personnel, equipment, etc. (respectively reducing costs and improving efficiency) – in line with the existing demographic determinants of the Bulgarian population. The draft Health Map plans to open 6,230 new LTC beds nationwide. The current number of such beds is 1.8% of the total, and will be required to increase to 13%. The introduction of three new clinical pathways for prolonged treatment will, for the first time, allow each hospital to provide continuous care for their patients.

The National Long-term Care Strategy clearly recognizes the link between the healthcare system and social services in the provision of long-term care, and the need for better coordination and balance. The strategy for long-term care builds on policies aimed at creating conditions for an independent and dignified life for the elderly and persons with disabilities, and for respecting their rights, taking into consideration their capabilities and needs.

In Bulgaria, there are different kinds of social and health services for adults, including LTC, offered by the private sector. The personal pensions of older people are not adequate to cover the fees in private nursing homes and hospices. The funding of those services is completely provided by the family in the case of only about 1% of the population. Alternative finance may come from the state, local budgets, minimum usage charges, and European programmes. The big problem is **the lack of sustainability for these services**. In the case of those funded through European projects, only a small proportion of them continue to function after the project is closed as state services, and not with the same volume and quality of service.

State-funded services for adults and LTC are usually managed by municipalities. There are conditions for competition among service providers, which are registered with the Social Assistance Agency and the municipal enterprises for social services. Such a system ensures at least minimal resources tailored to local needs. The downside of this is the growth of corruption at local level, lack of uniformity in the range of services, and a very low quality of service.

2.3 Policy recommendations

The whole issue of work-life balance for carers, as well as the well-being of carers and their family members, remains largely under-researched in Bulgaria.

To improve work-life balance for carers it is necessary to **improve the facilities**, **institutions**, **and professional staff capacity** in health and social systems in Bulgaria, and to enhance the monitoring of compliance with the criteria and standards for provision of LTC services. Additional efforts to **improve coordination between the social and health systems** are necessary in order to achieve practical results and the provision of quality and affordable integrated services for the elderly and people with disabilities. Improved interaction between the social and healthcare systems is the key to providing good-quality medical care for patients who are in need of LTC. The construction and development of a model for long-term treatment, as well as integrated care, for patients with chronic diseases, will provide improvement in the quality of life of these people and their families.

It is imperative to establish clear **rules for the organization of palliative care**, guaranteeing the right to the relief of pain and suffering, the right to specialized care, and the right to emotional, social and moral support for the terminally ill and their family and friends. In this regard, we note the preparation of the medical standard 'Palliative care', which will be consistent with the recommendations of the European Association of Palliative Care for different levels of palliative care (at home, in a hospital, and in social institutions) and covers a range of mental and emotional aspects. This standard is important for the development of the process of creating good-quality and effective structures.

As disability and chronic disease are strongly correlated with poverty through many mechanisms, poor families are overrepresented among those who have a family member or children with disabilities or chronic diseases in need of LTC. Many of those families are left on their own without much support, and face many logistical barriers to obtaining medical help. If medical establishments were well-positioned and accessible, and had other services such as **transport from home or a home-based service**, this could have a very positive impact on the well-being of carers and their family members.

Financial and organizational sustainability need to be ensured for the application of LTC policies, and for LTC services developed in the community that currently rely on temporary financial sources.

However, there are currently many proposals on the political agenda in Bulgaria, together with on-going reforms in health and social areas, that will affect work-life balance for carers as well as the well-being of carers and their family members.

Greater involvement by trade unions in the issue of work-life balance is necessary. After Bulgaria's accession to the EU, Bulgarian trade unions participated in efforts to establish some transnational learning networks on work-life balance and were actively interested in the experience of other European countries such as Germany, Poland, Italy, and Romania¹⁸. But little improvement was achieved in the situation of carers, apart from more generous maternity leave.

There is a real need for in-depth studies and analyses of the employment effects for carers with dependent relatives, and of the overall effects of the existing LTC regime on the well-being of informal carers and the cared-for, in order to provide an evidence-base for continuation of the reforms.

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¹⁸ "(BILANCIA) Ref. No: VS/2007/0375", Confederation of Independent Trade Unions in Bulgaria, 2009, pp. 1-157.

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