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LONG-TERM CARE OF OLDER PERSONS AND PERSONS WITH DISABILITIES IN THE WESTERN BALKANS

The most important findings of the regional study created within the three-year project “Strengthening the resilience of the older persons and persons with disabilities during COVID-19 and future disasters” in the Western Balkans region.

The Western Balkans has been experiencing demographic ageing for several years due to declining birth rates, longer life expectancies, and rural-urban migration of working-age individuals to Western Europe and beyond. Although life expectancy in the region is 76.28 years, healthy life expectancy only averages at 67.26 years according to WHO data from 2019¹. This trend is expected to continue, highlighting the need for robust long-term care systems to accommodate the growing older population. Investing in long-term care not only improves quality of life for those in need but also supports informal/ family caregivers to return or remain in the workforce.

As part of the three-year initiative “Strengthening the resilience of older persons and persons with disabilities during COVID-19 and future disasters,” SeConS Development Initiative Group² conducted a study on the long-term care systems in the Western Balkans. The aim of the study was to develop recommenda-

tions for strengthening service providers and civil society organizations (CSOs), improving public policies, and increasing financial benefits to enhance long-term care for older persons and persons with disabilities during regular periods as well as emergencies such as the COVID-19 pandemic. In addition to the regional study, local studies were developed for each project site within the initiative.

This innovative research utilized a consistent methodology across Serbia, Albania, Bosnia and Herzegovina, North Macedonia, Montenegro, and Kosovo*. The methodology included a desk analysis of regulations and publicly available data, as well as quantitative research involving 550 older adults and 100 persons with disabilities (PWD) in need of long-term care, or a total of 3,900 subjects across all project sites. Additionally, the research included qualitative interviews with service providers, institutional representatives, and long-term care service users.

¹ World Health Organisation (WHO), Life expectancy and Healthy life expectancy– Data by country.

² <https://secons.net/en/>

* This designation is without prejudice to positions on status, and is in line with UNSCR 1244/1999 and the ICJ Opinion on the Kosovo declaration of independence.



WHAT IS LONG-TERM CARE?

“Long-term care is defined as a set of services and forms of support for persons who, due to mental and/or physical fragility and/or disability over a prolonged period of time, depend on support in performing activities of daily living and/or need more permanent medical care. Daily activities where support is necessary may include personal care activities that someone needs to perform on daily basis (activities of daily living such as bathing, dressing oneself, eating, getting out of bed or chair, going to bed, moving, using the toilet, controlling bladder and bowel functions), or instrumental activities of daily living (such as preparation of meals, money management, shopping, household maintenance and telephone use)” (EC,2021).

There are no unified systems of long-term care in the Western Balkans. Instead, components of such care are distributed across both social welfare and healthcare systems. In the region, social welfare is considered the primary source of long-term care, while healthcare is considered a complementary activity. The Western Balkans region has two distinct models when it comes to long-term care. Albania and Kosovo consistently adopt the principle of personal and family responsibility, with partial state

funding provided for long-term care services. Conversely, in North Macedonia, Serbia, Montenegro, and Bosnia and Herzegovina, social welfare rules prioritize self-care and care by family members. However, an exemption is made for long-term care, as the right to financial allowances for custodial care and assistance implies the right to long-term care from public funds. In this case, support is provided without prior consideration of the beneficiary’s financial situation or availability of family support.





REGULATING LONG-TERM CARE IN THE WESTERN BALKANS

The regulation of measures and services aimed at supporting individuals who are unable to perform daily activities varies across the Western Balkans, with some countries having centralized legislation for both social welfare and healthcare, while others have a more complex state-administrative framework. For instance, Montenegro, Kosovo, and North Macedonia have centralized legislation for both social welfare and healthcare. In Serbia, healthcare is regulated at the central level, while social welfare is determined by a single national regulation, with local authorities responsible for further regulating the conditions for providing services in the community from local self-government funds. The legislation for long-term care in Bosnia and Herzegovina is subordinate to a complex state-administrative framework and under the jurisdictions of entities and/or cantons.

Assessment of beneficiaries' needs in the Western Balkans region is managed at the central level. However, one of the most significant issues in the Region is separation of the assessment of the needs for health care and social welfare services, resulting in the lack of coordination between the systems of health care and social welfare.

The quality of long-term care in the Western Balkans is ensured through the development of standards and rigorous monitoring of their implementation. Health care service standards have a long tradition in all of the countries and all of them have developed

procedures for application and improvement. However, standards for the provision of social welfare services are relatively recent and are not fully established in practice.

Long-term care management

Long-term care management in the Western Balkans is predominantly decentralized and uneven. Central authorities are responsible for the management of financial allowances and health care services, while social welfare services management is divided between local and central levels. However, there are significant differences in the capacities of local authorities to manage long-term care, which is a common characteristic in the Region. Additionally, uneven economic development between local administrative units is evident throughout the Region in the context of long-term care.

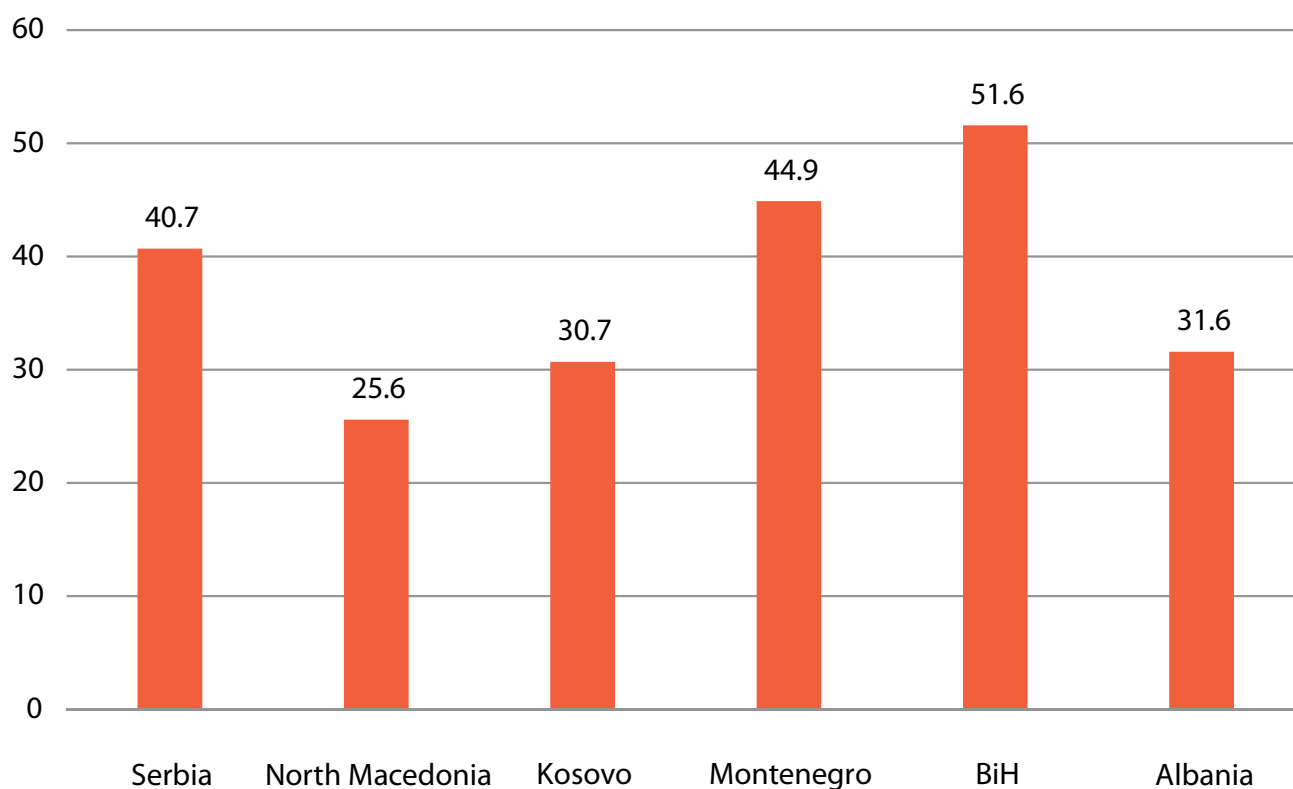
Long-term care financing

Long-term care in the Western Balkans is typically financed through a combination of three sources: taxes, insurance, and citizens' own money. However, the proportion of funding from each source can vary. In practice, the availability of social welfare services in local communities is largely dependent on funding from central budgets, as demonstrated by past experiences in the region. Additionally, citizens throughout the region often contribute their own money towards both health care and social welfare services.

According to the findings of the regional research conducted by SeConS in 2021³ share of persons over 65 years old in the Western Balkans who are in a need for long-term care due to the great difficulties in their daily functioning differs significantly between countries.

North Macedonia has the fewest older persons who experience major difficulties in performing activities of daily living. While, on the other hand, data from Bosnia and Herzegovina indicate that more than half of the respondents stated that they face major functional difficulties.

Graph 1: Share of persons older than 65 with major difficulties in performing activities of daily living (%)



Source: SeConS, Research on the access to long-term care in the Western Balkans, 2021

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3 Research on availability of long-term care in the Western Balkans.



WHAT IS FORMAL LONG-TERM CARE?

Formal long-term care in the Western Balkans region consists of services within the social welfare and health care system and financial allowances. Services can be classified into residential services, daily services, and services in the beneficiaries' homes.

Residential social welfare services⁴ in the Western Balkans are provided to a wide range of beneficiaries and are not exclusively for beneficiaries who need long-term care. By providing these types of services, the basic social, cultural, and recreational needs are fulfilled throughout the Region as well as the needs for medical care and support in performing activities of daily living due to the decrease of the beneficiaries' functional capacities. Albania is the only one in the region that specifically singles out "long-term accommodation" in its classification of residential services as a form of support for people in need of long-term care.

According to the capacity volume in residential institutions for long-term care, the Western Balkans region is ranked at the bottom of the European list. Moreover, in relation to the population numbers, Kosovo has the smallest capacities for long-term care in Europe, while Serbia stands out a bit from the rest of the Region and has greater capacities than 10 European coun-

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4 "Residential care includes institutions that are primarily engaged in providing residential long-term care that combines supervision, medical, or other types of care according to the beneficiary's requirements. In these institutions, a significant part of the procedure and care provided is a mix of health and social services, where health services are largely at the nursing level, combined with personal care services. The medical components of care, however, are much less intensive than those provided in hospitals" (Eurostat, 2020).

tries⁵, largely due to the expansion of the private sector in this area.

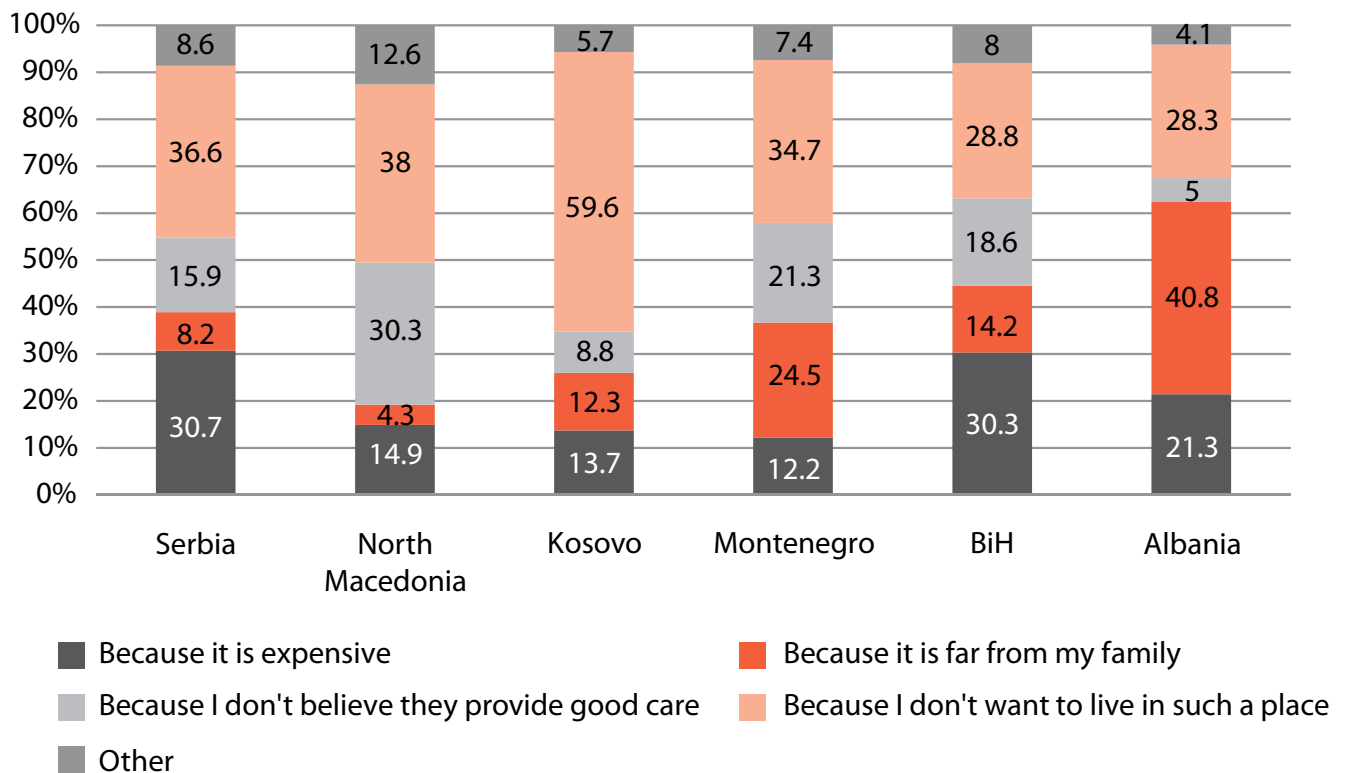
Based on regional surveys, most Western Balkans citizens who struggle with activities of daily living prefer community services over residential care services.⁶ However, one-fifth of Albanian respondents and one-fourth of Bosnian and Herzegovinian respondents find residential services acceptable. In Kosovo and Montenegro, only 7 to 11 percent of citizens needing long-term care prefer residential services.

Citizens in the region have varying reasons for their reluctance to use institutional placement services, but a common factor is their subjective resistance to the long-term care institutional model, often stemming from prejudices against residential placement. Approximately two-thirds of respondents over the age of 65 in Serbia, Montenegro, and North Macedonia stated that they do not want to live in a long-term care institution. In Kosovo, this percentage is slightly lower at 59.6%. For older persons in Albania, the most important reason for not wanting to live in an institution is the distance from their family, while in Montenegro, it is the second most important reason. In North Macedonia, about one-third of respondents do not trust the quality of the service provided by placement service providers, while one-fifth of respondents in Montenegro share this attitude.

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5 Latvia, Croatia, Romania, Poland, Montenegro, North Macedonia, Greece, Albania, Bulgaria, Kosovo.

6 SeConS, Research on the access to long-term care in the Western Balkans, 2021

Graph: Reasons why the respondents older than 65 would not want to use the placement service (%)



Source: SeConS, Research on the access to long-term care in the Western Balkans, 2021

The reasons why older citizens in the Region would opt for institutional placement services differ greatly, but the common factor is the reduced ability to care for themselves.

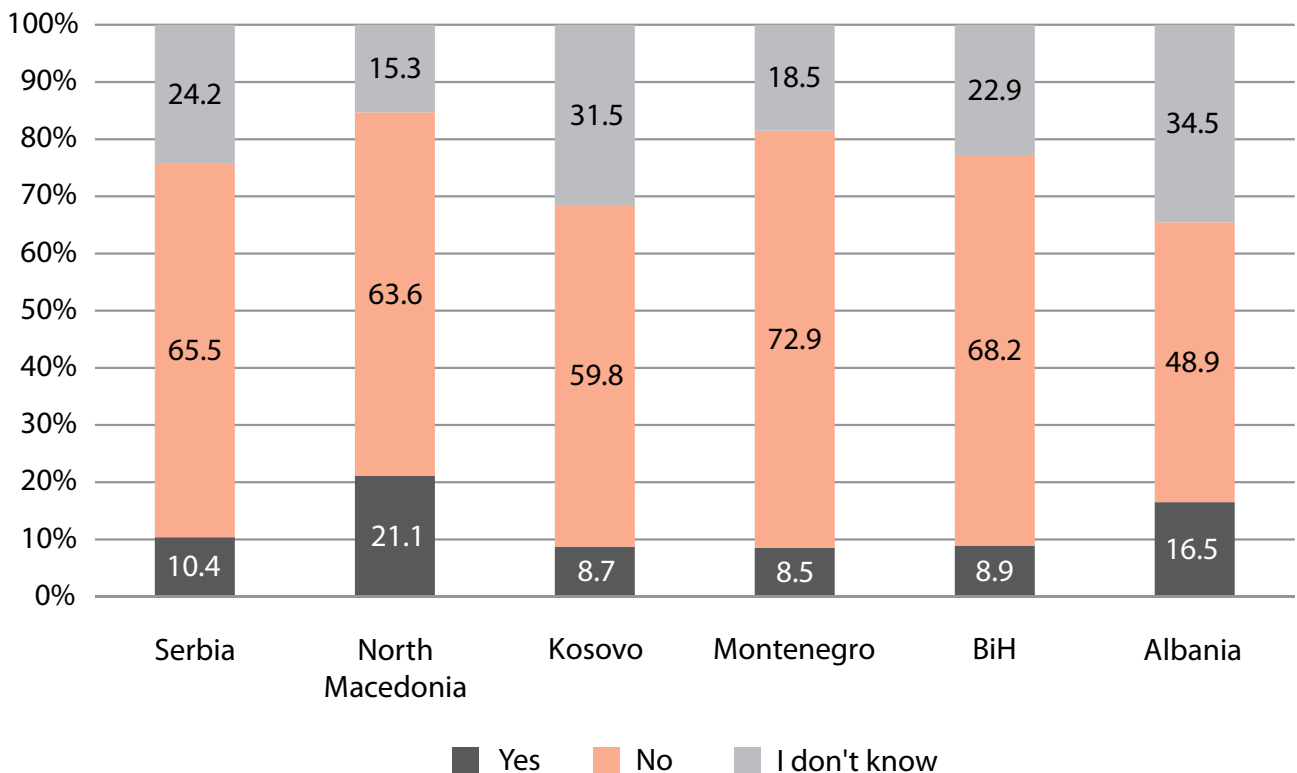
This is the dominant reason in Albania, but it is also important for the respondents that they are not alone. Older citizens in Bosnia and Herzegovina, North Macedonia and Serbia emphasize the availability of health care as the prevalent motive. The expectations of respondents in Montenegro and Kosovo from placement in an institution are mostly aimed at reducing the feeling of loneliness.

People over 65 in the Western Balkans rarely consider family accommodation/ foster care as a way to meet the need for long-term care, except in Albania and Kosovo, where family accommodation/ foster care is a form of residential service that is part of

the social welfare system.⁷ The respondents from Montenegro and Bosnia and Herzegovina are the most determined in their opinion, where more than two-thirds of older persons indicated that they would not consider this service. On the other hand, compared to other parts of the Region, the North Macedonia older persons display the most affirmative attitude towards family accommodation/ foster care – slightly more than a fifth of older persons indicated that they would consider family accommodation/ foster care as a type of service. Those who said they would consider family accommodation/ foster care cited the inability to take care of themselves as before and loneliness as their main reasons.

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7 SeConS, Research on the Access to long-term care in the Western Balkans, 2021.

Graph: Readiness to provide family accommodation/ foster care service, 65+ (%)



Source: SeConS, Research on the access to long-term care in the Western Balkans, 2021

Just like older persons, PWDs in the entire Region do not show willingness to use the family accommodation service/ foster care. Respondents from Montenegro once again show the greatest determination in their attitude (88%), while respondents from Kosovo and Albania show the greatest indecision. The inability to take care of themselves as before is also highlighted as the main reason for using this service.

Home-based services

The most commonly expressed need among citizens in the Region is for home-based services. This service, which is significantly available only in Serbia and sporadically provided in other parts of the Region, is used by less than 1.5% of PWDs and about 8% of persons over 65

who reported severe limitations in performing daily activities, even in Serbia where it is the most widespread in the Western Balkans.⁸

Despite a prioritization of home assistance in public policies throughout the Region, there are generally insufficient capacities to meet the demand for these services. Available reports indicate that in most of the Western Balkans region, the provision of home assistance services is predominantly based on the project activities of national and international non-governmental and humanitarian organizations. Also, a common characteristic that burdens the provision of this type of service is the lack of management, professional and financial capacities within the local communities.

⁸ SeConS, Research on the access to long-term care in the Western Balkans, 2021.

The market for home assistance services in the Western Balkans is underdeveloped. Although all demand-related factors indicate that there is a need for this type of support, the majority of citizens who need help in performing activities of daily living, are unable to afford professional services due to low income. Public funds allocated for this purpose, judging by the number of beneficiaries, are insufficient. Additional challenges include the black/informal market for these services, which leads to the provision of services that are cheaper but often of questionable quality, without the possibility to monitor them, as well as the migration of professional caregivers to EU countries, which will lead to a lack of formal, professional caregivers in the near future.

The licensing process for home assistance services, which would ensure the implementation of standards for the provision of such services, is difficult in the entire Western Balkans region, except in Serbia. This prevents adequate data collection and evaluation because a significant share of home assistance services is provided through projects outside the reach of official records or in the informal market. On the other hand, in Serbia, the licensing procedure of service providers has been applied since 2014, so the offer is significantly more stable and subject to evaluation.

Day services within the community

Day care centers, which are an important segment of the long-term care system, are rare in the Region. Albania has 34 centers⁹, Montenegro 19, in North Macedonia there are 27-day centers across the country, including social clubs and community mental health centers.¹⁰ In Serbia, 44 organizations¹¹ were licensed to provide

day care services to adult beneficiaries in 2021. There is no precise data on beneficiaries and capacities of day services in Bosnia and Herzegovina and Kosovo. One of the key obstacles to greater availability of this type of service is the physical distance of beneficiaries. The services provided in the community should also be viewed from a prevention perspective. In previous decades, in most of the region, there was a widespread practice of organizing clubs for older persons, whose activities significantly contributed to preventing and slowing down the need from becoming too great. Considering that over time this practice has been neglected, its re-establishment should be considered.

Financial allowances for long-term care

Financial allowances directly intended for long-term care in the Western Balkans exist in Bosnia and Herzegovina, Montenegro, North Macedonia, and Serbia. In these parts of the Region, financial allowances are provided through compensation for custodial care and assistance. This benefit is usually paid in two different amounts depending on the level of disability. The higher amount is usually intended for beneficiaries with the most severe disabilities and the most complex mental issues. The conditions for obtaining this type of support differ in the Region according to the needs assessment method.

The adequacy of financial allowances depends on the intensity and type of care. If it is the most complex type of care, then it should be taken into consideration that higher amounts¹² are not sufficient for the costs of residential services. This becomes especially prominent considering the in-

9 International Labour Organisation, 2022.

10 Republic of North Macedonia, Ministry of Labour and Social Policy, 2018.

11 Republic of Serbia, Ministry of Labour, Employment, Veteran and Social Policy (s.a.)

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12 Higher amount implies what is called in Serbia increased custodial care allowance. It is important to note that there is a difference in the name of this type of aid but that its purpose is the same.

creased expenses of the household due to the disability of one of its members.

Compensation for custodial assistance and care is predominantly used to ensure basic living conditions rather than to provide the necessary

services. There is no doubt that long-term care benefits should be better synchronized with services. Also, it is necessary to focus policies on supporting persons with functional limitations and low incomes, because only then can financial allowances for long-term care fulfil their intended function.



WHAT IS INFORMAL CARE?

Informal care is the dominant form of long-term care and there is no indication that formal care will take over that role even in the long term.

Informal care is the care provided by informal caregivers, such as relatives, spouses, friends, and other people, usually without any compensation, outside the formally contracted relations and at the home of the care beneficiary (EC, 2018).

Long-term care in the Western Balkans traditionally relies on the family. All regulations in the Region dealing with family relations establish the obligation to support the closest relatives. Regulations in the field of social protection are based on the individuals' primary responsibility for taking care of themselves and their families, while state assistance is provided when support within the family is not available.

In the Western Balkans, support in performing activities of daily living is predominantly provided by household members. Almost all respondents in Albania and Kosovo rate the support of persons living in a joint household as the most important.¹³ In other parts of the Region, family members who live outside the household play a significant role in providing support, especially to older relatives. They provide key support for about one third of older persons with major functional

difficulties in Serbia and Montenegro, and for one fifth of respondents over 65 in North Macedonia and Bosnia and Herzegovina. However, their support is less pronounced in the case of persons with disabilities, primarily because it is a population that more often lives together with their children or parents who help them.

It is characteristic of the entire Western Balkans that a small proportion of citizens with functional difficulties rely exclusively on professional support. Paid assistance is crucial for 17.6% of surveyed PWDs in North Macedonia and 11.5% and 8.1% in Serbia and Bosnia and Herzegovina, while it is almost negligible for older persons over the age of 65, the exception being Bosnia and Herzegovina, where paid support is crucial for 11% respondents from this age group. Taking into account that formal long-term care services are not sufficiently available in the Region, this may indicate the importance of the market for informal care services, especially home assistance that functions in the informal grey or black zone.¹⁴

Informal care is not the focus of public policies in the Western Balkans. Even though the crucial importance of informal caregivers in providing long-term care is clearly expressed, this phrase is rarely found in public policy sources.

Financial allowances for informal caregivers are established only for parents or guardians who care for children with functional difficulties. North Macedonia and Serbia have a pro-

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13 Ibid.

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14 Ibid.

gram that provides financial compensation in old age to parents or guardians after a long period of care. Montenegro and Bosnia and Herzegovina established the status of parent-caregiver in cases of the most severe forms of disability, which includes payment of a monthly allowance equal to the minimum wage. In BiH, this benefit is paid in the amount of the minimum wage, while in Montenegro it is about 60% of the minimum wage. Longer absence from work to provide care is most often made possible in the case of childcare. Bosnia and Herzegovina and Montenegro have statutory paid short-term leave to care for an adult

member of the immediate family or household, as is the case in Serbia.

Long-term care services can be seen as support for informal caregivers in a broader sense. Most of the services that contribute to the long-term care of beneficiaries are also support for informal caregivers, such as day care or respite accommodation services. On the other hand, services such as family accommodation/ foster care practically give informal care a formal character. By providing a family accommodation/ foster care service, the informal caregiver becomes a formal service provider.



This document was developed from a study created within the three-year project "Strengthening resilience of older persons and persons with disabilities during COVID-19 and future disasters".

The project is coordinated by the Red Cross of Serbia and supported by the European Union, Austrian Development Agency and the Austrian Red Cross.

It was launched at the end of 2020, and connects civil society partners from Serbia, Albania, and Bosnia and Herzegovina, Montenegro, North Macedonia and Kosovo, as well as large civil society networks representing older persons and persons with disabilities at the level of the European Union.*

The consortium of projects consists of: Red Cross of Serbia, Austrian Red Cross, Albanian Red Cross, Albanian Association of Geriatrics and Gerontologists, Red Cross Society of Bosnia and Herzegovina, Association for Help and Development HAJDE, Red Cross of Montenegro, Union of the Blind of Montenegro, Red Cross of the Republic of North Macedonia, Association Humanity, Caritas Kosova, National Organisation of Persons with Disabilities of Serbia, SeConS Development Initiative, AGE Platform Europe, European Disability Forum.



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