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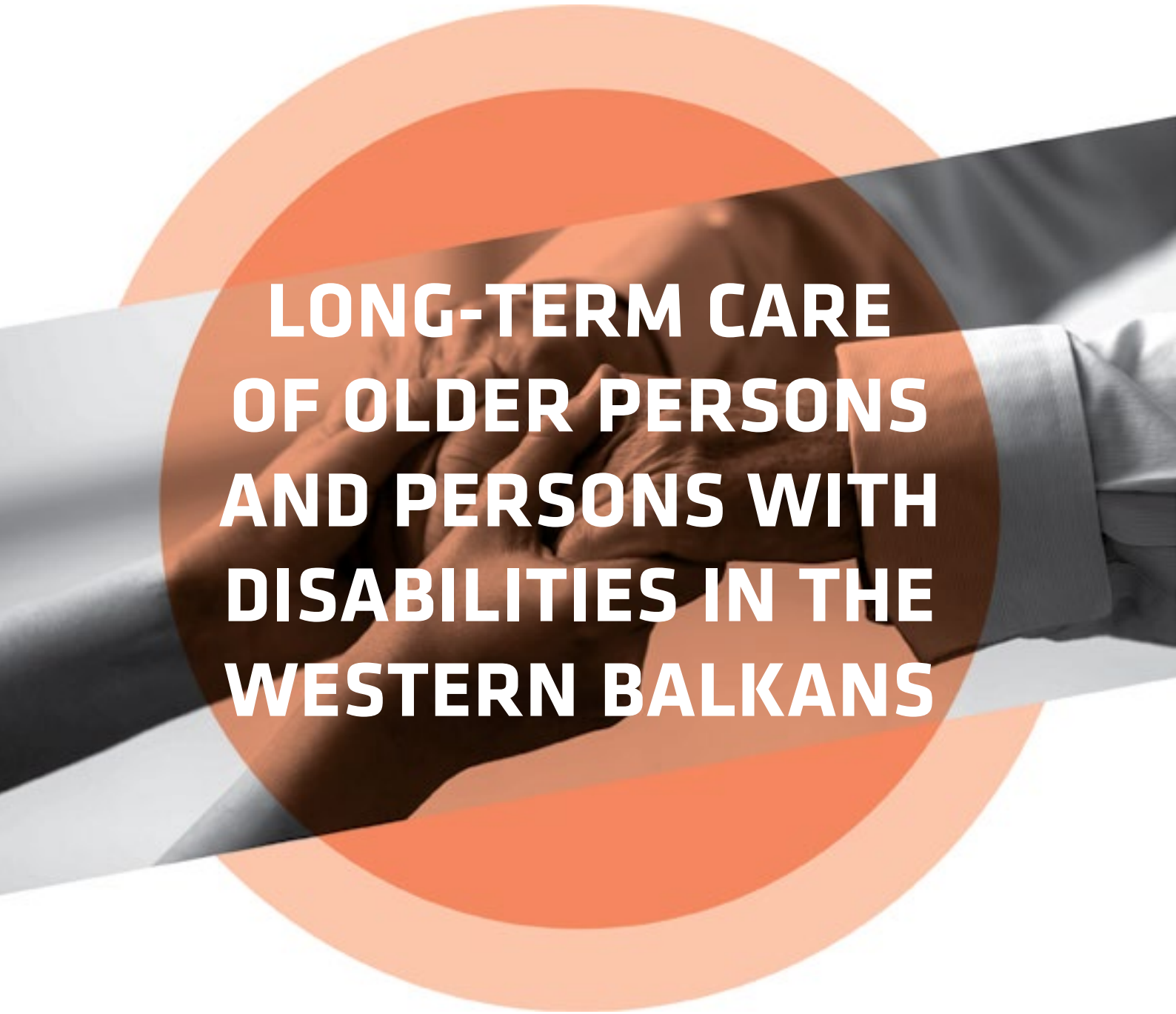

LONG-TERM CARE OF OLDER PERSONS AND PERSONS WITH DISABILITIES IN THE WESTERN BALKANS

DRUŠTVO CRVENOG KRSTA/KRIŽA BOSNE I HERCEGOVINE
ДРУШТВО ЦРВЕНОГ КРСТА/КРИЖА БОСНЕ И ХЕРЦЕГОВИНЕ
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NACIONALNA ORGANIZACIJA OSOBA SA INVALIDITETOM SRBIJE

Хуманост

Udruženje za pomoć i razvoj
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LONG-TERM CARE OF OLDER PERSONS AND PERSONS WITH DISABILITIES IN THE WESTERN BALKANS

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LIST OF ABBREVIATIONS

ABBREVIATIONS	DESCRIPTION
ADLs	Activities of Daily Living
CATI	Computer-assisted telephones interviewing
SWC	Social welfare centre
DG EMPL	European Commission Directorate-General for Employment, Social Affairs and Inclusion
EHIS	European Health Interview Survey
EU	European Union
EU – SILC	European Union Statistics on Income and Living Conditions
EC	European Commission
EU	European Union
HALE	Health Adjusted Life Expectancy / Healthy Life Expectancy
IADLs	Instrumental Activities of Daily Living
NGO	Non-governmental organisation
CSO	Civil society organisation
PWD	Persons with disabilities
SPC	Social Protection Committee
PDI	Pension and disability insurance
UN	United Nations
WHO	World Health Organisation

This study was developed as part of a three-year initiative in the Western Balkans region entitled "*Strengthening the resilience of older people and people with disabilities during COVID-19 and future disasters*". The project is coordinated by the Serbian Red Cross and supported by the European Union, the Austrian Development Agency and the Austrian Red Cross. Launched in late 2020, the project connects civil society partners from Serbia, Albania, Bosnia and Herzegovina, Montenegro, Northern Macedonia and Kosovo*, as well as large civil society networks representing older people and people with disabilities at the EU level.[1] Wtihin this project as one of the project partners, SeConS – development initiative group is in chargefor the research component and formulation of recommendations with the purpose of strengthening the resilience of older persons and persons with disabilities (PWD) in the Western Balkans during Covid-19 and future disasters and development a study of the situation in this area.

The aim of this study is to provide insight into the facts that will enable the formulation of recommendations and measures for public policies that would be aimed at how to increase the capacities of service providers and civil society organisations (CSOs), but also to increase financial contributions to ensure better access to long-term care services for older persons and people with disabilities under normal circumstances, and especially in case of emergencies. In addition, this study provides a comparative overview of the condition of long-term care in the Western Balkans and shows similarities and differences, thus enabling mutual learning and finding solutions.

* 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.

1 The consortium consists of: Red Cross of Serbia, Austrian Red Cross, Albanian Red Cross, Albanian Association of Geriatricians and Gerontologists, Red Cross Society of Bosnia and Herzegovina, Assictance and Development Association HAJDE, Red Cross of Montenegro, Association of the Blind Montenegro, Red Cross of the Republic of Northern Macedonia, Association Humanost, Caritas Kosova, Serbian National Organisation of Persons with Disabilities, SeConS Development Initiative Group, AGE Platform Europe and European Disability Forum.

RIGHTS-BASED LONG-TERM CARE: A COMMON PAN-EUROPEAN CHALLENGE

A foreword by AGE Platform Europe

Long-term care policies are undergoing a paradigm shift across Europe, and across the world. The discussion and implementation of the UN Convention on the rights of persons with disabilities has already started a transition, from previous models that either left families alone with the burden of care for a person with a disability or separated persons with disabilities from the rest of society in closed institutions. A rights-based approach, aiming for the full participation of persons with disabilities in society in all their independence is now the policy ideal towards which service providers and governments strive – with all the difficulties, setbacks and resistances that this transition entails.

Too often, a distinction is made between older persons in need for care and persons with disabilities. Excluding persons with disabilities from society at a younger age is deemed less acceptable than excluding older persons with impairments. As long as old-age is associated with frailty, older persons in need for care are hit by both ageism and ableism – given most older persons in need for care are women, gender inequalities are further reinforced by this attitude.

Across Europe, care for older persons needing support is borne 'by default' by families. This cannot be considered as a fatality, but should be thematised as a political choice, which is the result of a fallacy: the idea that unpaid, informal care is cheap. It has however a tremendous cost for families, either if they pay for private services or, more often, provide the care needed by themselves: informal carers are less likely to be able to work, have a higher risk to their mental and physical health and higher risk to face poverty and social exclusion. In most cases, this unpaid care is provided by women. The choice of public policy to rely on informal care is also what appears from the country studies in this present report. The OECD estimates that 80% of care work is performed this way. This does not do justice to persons in need for care, nor their families. It also does not do justice to the work of professional carers, as the reliance on familial care models perpetuates the idea that care work can be done 'for free' and without training – and therefore that professional care can be paid inadequately and performed by undertrained staff in difficult working conditions.

Given the rapid transformation of our societies' age structures, it is high time to question this familial model and to develop long-term care as a strong and legitimate pillar of social protection. States have subscribed to the UNCRPD and other human rights instruments that call for the respect, protection and promotion of the integrity of persons. Providing enabling services, which help a person to maintain her independence and autonomy is therefore an obligation, not a luxury. Given the distribution of the risk to develop a care need – tilted towards women,

low-income workers and groups who do not enjoy equal opportunities such as Roma, the responsibility for funding care must be put on the larger shoulders of societal solidarity mechanisms. A fragmentation of responsibility for care provision and funding on the municipal level cannot ensure this solidarity.

Similarly, the perceived value of care must be increased. Ensuring a persons' highest good, independence and integrity, is a valuable task that needs specialised knowledge. On top of skills that are specific to age-related diseases and disabilities, emotional skills – being present for a person ––, communicational skills – being part of a wide, interdisciplinary team around a person in need of care encompassing specialist doctors as well as household services –– and digital skills have to be better integrated into all professions in the care ecosystem. Similarly, the responsibility for a person in need of care needs to translate into an adequate status for care workers.

These issues of quality, affordability, skills and working conditions are at the heart of the European Care Strategy, announced in September 2022. Through the Strategy, the EU institutions have set up quality criteria and committed to develop indicators for quality, affordability and accessibility of care services. As all European States are facing similar issues in ensuring dignifying care, it is very helpful that a European process is launched to inspire, transpose good practices and measure progress. AGE has called on EU level for an Age Equality Strategy, which would go even further than the development of a European approach to care: it would link policy areas which are currently not connected, but which all contribute to the possibility of active and healthy ageing: transport, urban, rural and digital environments, accessibility of essential services such as banking, health services or public authorities. Many needs for long-term care can be prevented by strengthening prevention, health promotion and accessibility, and by making care rehabilitative rather than curative only.

We hope that the facts revealed by this study contribute to a similar reflection on national level to ensure that all persons, regardless their age or care need, have the same rights to participate in society.

Philippe Seidel Leroy
AGE platform Europe

1 INTRODUCTION

Demographic ageing is one of the key trends of the 21st century and the region of Western Balkans has been experiencing its effects over the past several years through a combination of lowered fertility rates, extended life expectancy of the population as well as migration of work-age population – internally from rural areas to cities, and externally to the countries of Western Europe and beyond. The demographic ageing has increased life expectancy across the region but the number of years expected to be spent in good health has not risen proportionally. In the region of Western Balkans, life expectancy is on the average 76.28 years while healthy life expectancy averages at 67.26[2]. The gap of 9.02 years between these two figures is the period of life in which the needs for services of long-term care become regular and increase with time. As a comparison, in the European Union this gap is approximately 16 years with the life expectancy being 80.4[3] and healthy life expectancy in this region being 64[4]. Therefore, considering the continuing population ageing and projections for the coming decades that all predict further increase of the older cohorts in the overall populations across the region it is important to build robust systems of long-term care to ensure adequate capacity and planned growth of this capacity. Investing in long-term care will not only increase the quality of life of persons in need of care but will also provide a lateral benefit by supporting informal/ family caregivers in returning to the labour market or not having to leave it in the first place[5].

There is no unique definition of long-term care but what is shared between different systems of long-term care and what should be their objective is, as World Health Organisation states in its Framework for countries to achieve an integrated continuum of long-term care: "to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity"[6]. As functional decline is placed on a broad spectrum the long-term care services are typically grouped in three categories: health care, personal care and social needs.[7]

According to the WHO, the characteristics of the well-functioning long-term care systems are that they are appropriate, affordable, accessible and uphold the human rights of both older

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

3 Eurostat, 2022.

4 Eurostat, 2023.

5 WHO, 2022.

6 WHO, 2021.

7 Ibid.

persons and their caregivers.[8] As the needs of persons for long-term care are diverse and change over time, the systems should be ensuring the continuum of care in order to provide uninterrupted care between different providers and roles (prevention, rehabilitation, palliative care acute care), different levels of intensity as well as between different settings (home-based care, community care, institutional care etc.). Ideally the systems should be integrated, encompassing both healthcare and social care services with a single entry point for users and well-coordinated so that the services are received in a non-fragmented manner.[9]

In order to achieve well-coordinated, appropriate and accessible systems of long-term care services, the policy creators should be addressing the following main issues present across the region of the Western Balkans:

- **Fragmentation of services:** the services are typically provided through separate systems of healthcare and social protection, coordinated by different ministries with separate strategies, development plans, budgets etc. For the clients of these services, this means having to deal with several different types of administration at multiple levels as they navigate institutional care, community-based care, different kinds of support etc. Integrating these systems – including sharing of information and coordinated care delivery – as well as ensuring single point of entry and smooth interaction wherein the client receives the services in a non-fragmented way would be consistent with upholding the clients' human rights and dignity.

- **Limited scope and variety of services:** there is a small number services available across the region, especially in terms of community-based care. This means that many care needs are not satisfied and as a result, the desired quality of life and independence of function of clients are not achieved. Increasing the scope of services to meet a wider scope of needs is crucial to achieve the continuum of care that will adequately follow the continuing development of needs across the life course.

- **Insufficient capacity of services:** there are long waiting lists across the region for many of the long-term care services, which is a result of the lack of professional caregivers as well as of the general fragmentation of the LTC systems. This is especially visible in the rural areas where migration of younger population has created pockets of depopulation and the capacity to provide even basic services is frequently close to zero. There is the need to increase the capacities both by ensuring more trained caregivers of different profiles are available in the workforce, but also by looking into intrinsic capacities inside depopulated areas and providing training and other kinds of support to ensure they are used effectively to provide care.

8 Ibid.

9 Ibid.

- **Caregiver workforce has skills-gap and is migrating outside of the region:** There is a clear need for better investments in both training and supporting the professional caregivers across the region. Current trend of their migration to Western Europe testifies of low salaries and therefore low motivation to stay in the national workforce. Additionally, there is a wide gap between highly skilled caregivers such as nurses who are medical school graduates and low-skilled ones who have received several weeks of training. This gap should be narrowed also by developing new caregiver profiles that would have both medical and social protection competencies and these would be especially effective in rural and remote areas that are harder to reach.

- **Informal caregivers are under-recognised:** despite being the backbone of every system of long-term care, informal caregivers are not recognised sufficiently. Providing them with training, counselling, support in formal services and more flexible labour market conditions would increase the quality of care as well as their own life, leading to lower risk of burnout and elder abuse.

- **Under-regulated private market of services:** many private service providers across the region are working outside of the scope of applicable regulation, providing services without license and undercutting the licensed providers with low prices. This not only destabilises the labour market and encourages migration but also increases the risks on the side of clients of receiving inadequate or even harmful services. Better regulation and monitoring mechanisms are therefore needed.

- **Data collection and analysis need to be improved:** as the older population is the most diverse demographic group and their needs for long-term care change over time, there is a need for much more thorough and systematic collection of data related to their needs and preferences as well as disaggregation by gender and by age, separating the data into five year cohorts for best results.

1. HOW DID THE STUDY COME ABOUT?

The analysis provides an overview of the situation regarding long term care in the Western Balkans. Study is based on the data collected in several phases and by applying several methods:

Desk analysis

The desk analysis presents an overview of long-term care regulations, relevant publications, publicly available data on the capacity to provide various long-term care services and the number of beneficiaries for each of the project locations. The desk analysis aim was to show how long-term care is integrated into the social and health care systems and to present the current conditions of functioning in the area of long-term care in each of the locations included in the project.

Quantitative research[10]

The research was conducted in each project location[11] on a sample of 650 older and disabled persons (PWD) in need of long-term care or the total sample of 3.900 subjects for all locations (the total number of persons contacted in the first phase of data collection was 7.289). Since people over the age of 65 and PWD aged 18–64 are most in need of long-term care and welfare, the sample was designed to include 550 persons over the age of 65 and 100 PWD in need of long-term care. The research was done with CATI (Computer Aided Telephone Interviewing) data collection method. In order to include only those in need of long-term care in the sample, the respondents were asked before the start whether they have certain difficulties that result in them needing support (visual and hearing impairment, trouble with moving, etc.), as well as whether they need the support of others in their daily functioning regardless of their difficulties. In case when the respondent was not able to participate in the survey due to illness or other physical impairment, a questionnaire on the needs and services used by the respondent was conducted with their legal guardian. During the research process, the highest ethical principles were respected, which imply voluntary participation and anonymity of the participants.

Qualitative research

At each project location, in-depth interviews were conducted with long-term care providers and representatives of relevant institutions in charge of formulating policies in the area of

10 Data collection for the qualitative reserach in the entire region wad undertaken by SMART Plus Research.

11 Serbia, Montenegro (CG), Bosnia and Herzegovina (BiH), Albania, North Macedonia and Kosovo.

long-term care, as well as beneficiaries of long-term care services. The aim of this part of the research was to review in more detail the findings obtained by quantitative research and to identify points that can be improved in the functioning of long-term care systems from the perspective of decision-makers and service beneficiaries themselves.

A study was done for each project location, available in the local and English languages. The data in this report has been innovated and updated compared to the data that can be found in the national studies.

2. WHAT WE NEED TO KNOW IN ORDER TO UNDERSTAND LONG-TERM CARE

For approximately two-thirds of older persons, there is a high likelihood of them needing support in performing activities of daily living and long-term care services[12]**.** Demographic ageing is a characteristic of modern societies. On a global level, it has led, on the one hand, to an increase in the need for support for people who cannot independently perform daily activities, and on the other hand, to an increase in the need to develop a system of formal care services and strengthen the support for informal caregivers. In such circumstances, there is an inevitable increase in expenditures, primarily in the field of health care and social welfare, which results in most modern countries facing challenges of financial sustainability of long-term care programmes and constantly searching for more efficient and effective solutions. However, the lower level of socio-economic development of the Western Balkan region compared to the European Union (EU), along with the consequences of accelerated demographic ageing, leads to an increased need for long-term care services.

> *"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).

When reviewing the needs, a classification into two groups of activities that people cannot perform independently is usually used in the context of long-term care. The first group consists of the so-called activities of daily living (ADLs) which include moving within the apartment, eating, dressing, using the toilet, maintaining personal hygiene, etc. simple activities in the immediate environment. Instrumental activities of daily living (IADLs) include managing personal finances, personal transportation, shopping and preparing meals, household maintenance, communication, and taking therapy. A group of health care activities that require certain medical competencies (wound dressing, measuring blood pressure, blood sugar levels, administration of a specific therapy) should be added to these. The European Union monitors long-term functional limitations of citizens in performing daily activities through the Survey on Income and Living Conditions (European Union Statistics on Income and Living Conditions – EU-SILC). This survey is conducted in the entire Western Balkans, except in Bosnia and Herze-

12 WHO, 2021.

govina. Another source of data in the EU, which includes functional limitations and limitations in the performance of activities of daily living as well as the use of appropriate support services, is the European Health Interview Survey (EHIS), which is conducted only in.

Persons who need support for independent living are within a side spectrum going from those who may need occasional support with purchases to bedridden patients who require extensive support. Such a wide range of needs is met through a system of long-term care services that includes both social welfare services and health care services, from the support that includes shopping or help in maintaining the hygiene of the apartment to round-the-clock care for a bedridden patient. This continuum of care therefore requires a wide spectrum of different services for beneficiaries with different needs, but also for a single beneficiary whose needs change over time. In order for the long-term care service system to effectively provide services along this continuum, caregivers with different educational profiles, and different degrees of competence and skills need to work for it.

The ageing of the population is undoubtedly the most important factor influencing the increase in the need for long-term care in the Western Balkans, as it is the case in the EU and many other parts of the world. The prominent ageing of the population of the Western Balkans is caused by a combination of reduced fertility and longer life expectancy, but also migration movements characterized by the outflow of the working-age population. The ageing of the population is most prominent in Serbia, primarily due to the long-term negative population growth i.e. the continually low fertility rate. Apart from Serbia, Bosnia and Herzegovina is the only country in the region that has had negative population growth throughout the past decade and the total fertility rate in this country is one of the lowest in the world. Also, BiH has a very prominent outflow of the working-age population due to migrations. Unfavourable demographic indicators in Montenegro are not as prominent as in previous countries, but they show that the trend of population ageing has affected this country as well. Also, the population of Albania and North Macedonia is ageing due to the influence of low fertility, but migrations from these two countries also have equal influence. Kosovo has the youngest population in Europe, however, the ageing of the population has the highest annual rate in the region. In this phase of the demographic transition, the ageing of the population in Kosovo is primarily influenced by migration. Although the ageing of the population affects the current need for long-term care in the region in different ways, it is clear that this type of support should be observed in the long term within the wider population policies that would channel the results of inevitable demographic changes.

The decrease in the share of the working-age population in the Western Balkans has a multifaceted impact on the long-term care demand. First, the capacity of informal care within the family that could be provided by members of the working population in the family is reduced. Demographic ageing, combined with migrations and greater participation of women in the labour market, leads to a smaller number of potential informal caregivers in the Region. Second, a decrease in working population numbers further endangers the social security system, which significantly relies on labour taxation.[13] In the Western Balkans, this has a particularly great significance due to the still very present informal employment. In addition,

13 Matković, 2017.

the potential risk of a decrease in public revenues due to a decrease in the share of the working population endangers the financing of support services for citizens with functional limitations. Therefore, long-term care public policies should be developed alongside public policies aimed at strengthening human capital in order for society to proactively face demographic challenges.

The labour market will inevitably influence long-term care policies in the Region. Economic indicators from 2011 to 2021 indicated the recovery of the labour market in the Western Balkans. Structural unemployment is already evident in the market in the Region characterized by the supply of unskilled labour . Gender differences in the labour market have been decreasing over time in the Western Balkans. They are still very present in Bosnia and Herzegovina and Kosovo, where there are significantly more unemployed women, who traditionally dominate as providers of long-term care services, while in Montenegro and North Macedonia, there is a higher proportion of unemployed men. Economic migrations of the population further diminish the labour supply in the field of long-term care in the Western Balkans. Demand in the EU, which has been attracting labour from the Western Balkans for decades, has been increasing precisely in the field of long-term care. Most of the EU member states have difficulties in attracting a sufficient number of workers to perform long-term care jobs, and nursing staff is in the first place among the occupations with employee shortages.[14] Long-term care in the Western Balkans, especially jobs related to direct interaction with the beneficiaries, is among insufficiently paid occupations, which increases the likelihood of this type of labour migration to EU countries. At the same time, long-term care in the Region cannot, for now, attract foreign workers. The previous approach of the rapid transformation of hard-to-employ groups of unemployed people with low work competencies into providers of long-term care services failed to produce obvious results. First, the long-term care market has gradually increasing demands in terms of competencies, and an experienced workforce that acquires these competencies during work easily finds positions in the long-term care markets that offer better conditions. The imbalance in the long-term care labour market in the Western Balkans has not yet turned into a crisis, but certainly represents a risk. Therefore, future policies should take into account the attractiveness of long-term care in the local and international labour market, taking into consideration that the increase in costs of employees in this area is almost certain. Apart from these challenges that the Region is facing, there is still a lot of room for improving the competences of both those who provide these services and those who would potentially want to provide them.

Some of the care services require medical educational profiles while other services require caregivers from the social welfare field with a wide range in terms of the duration and content of the training they need in order to provide the services effectively. In the Western Balkans, within this system, there are typically educational profiles in the field of social welfare on the one hand, and on the other, nurses with health care competencies, while there is a lack of professionals who would be somewhere in the middle, with competencies related to social welfare services but that can provide even simpler health care services, and whose impact would be particularly significant in remote and rural areas where reaching beneficiaries is more

14 Social Protection Committee (SPC) and the European Commission Directorate-General for Employment, Social Affairs and Inclusion (DG EMPL), 2021.

complicated and associated with higher costs. The exception is North Macedonia, where the Law on Social Welfare and its by-laws recognize the profile of caregivers and prescribe the necessary accredited training as well as other conditions for obtaining a certificate. In the rest of the region, there is a lack of professionals who would be somewhere in the middle, with competencies related to social welfare services, but who can also provide simpler services related to health care, and whose impact would be particularly significant in remote and rural areas where reaching beneficiaries is more complicated and associated with higher costs.

Health Adjusted Life Expectancy / Healthy Life Expectancy (HALE) in 2019, according to data from the World Health Organisation, in the Western Balkans ranges from 66 to 69 years. This indicator shows that it is necessary to further improve the quality of life, in order to extend the period of good health and thereby postpone the period of need for long-term care. The longest Healthy Life Expectancy can be expected in Albania, followed by Bosnia and Herzegovina, Montenegro and Serbia, where this indicator is around 67 years, and finally North Macedonia with the shortest Healthy Life Expectancy in Europe (data for Kosovo are not available). Although research indicates that Healthy Life Expectancy in the Western Balkans is between 66 to 69 years, the Western Balkans is at the bottom of the European scale. For comparison, among EU members, the average Healthy Life Expectancy was 72,6 years in 2019.

Health factors that affect reduced functionality differ throughout the Region. Among the top ten ranked diseases and conditions that result in death or disability in the Western Balkans, there are ischemic heart diseases and heart attack, as well as headaches, fall injuries, hearing impairment due to old age and colorectal cancer.

Long-term care in the Western Balkans is been formulated as a separate area of public policies. Although it is more than evident that this is a very current topic, decision-makers in the Region are more prone to a sectoral approach when formulating policies or determining measures to achieve outcomes of support for certain groups of beneficiaries such as the older persons or persons with disabilities. This way, certain segments of long-term care often overlap or details important for this type of support are missed. As a rule, public policies regulating health care and social welfare and the pension system are developed separately without mutual coordination. There is no doubt that the development of a uniform long-term care system would contribute to the efficiency, effectiveness and accessibility of this type of support. However, it should be taken into consideration that the establishment of a new system within the administrative mechanism of the state is an inevitably slow process that, as a rule, requires a series of changes that go far beyond the area that is the subject of reform – in this case, long-term care. Such an undertaking is desirable and can be implemented in the long term. However, in the short and medium term, it is more objective to focus on the formulation of uniformly framed long-term care policies that would be implemented in a synchronized manner through several administrative systems.

Even in EU countries, long-term care is not defined as a separate policy area, but it is included in various social and health policies and regulations.[15] European institutions

15 SCP & DG EMPL, 2021.

encourage decision-makers at the national level to synchronize public policies regulating long-term care with other related policies such as policies on pensions, health care, active ageing, etc. Institutions, regulations and social traditions of the Member States vary greatly in the field of long-term care. Some countries classify long-term care as part of social insurance, while in others it is treated as welfare assistance.

Health policies have a dual impact on long-term care. Less investment in preventive health care throughout life, especially in early childhood, increases the risk of needing long-term care services in the earlier period of life. This makes the health system reactive, so most of the health system capacity boils down to providing acute health care services in cases of complications or worsening of chronic conditions. The focus on the prevention of diseases and conditions that lead to reduced functionality in the Western Balkans is of key importance for long-term care. Although the Healthy Life Expectancy and life without major health problems is increasing in the region, the Western Balkans is still at the bottom of the European list according to this indicator, and additional measures are needed in order to prolong the time without the need for long-term care from a health care point of view. From the long-term care provision point of view, the priority is the availability of primary health care, especially home care, which is characterized by reduced capacity and low coverage throughout the Region. A large percentage of citizens with reduced functional capacities who cannot meet their health-related needs, especially in Albania and Serbia, indicates the need for improvement in this area. Even though in the Region, with the exception of Serbia, significant budget funds are allocated for health care, the level of allocation of citizens' own money for this purpose is still on average high and puts poorer social groups at risk. The increase in the share of public funds for health care in recent years should be attributed to more extensive budget expenditures due to the COVID-19 pandemic than to the overall improvement of health care. An additional challenge for health care in the Region is the increased number of medical professionals who migrate, primarily to EU countries, due to better working conditions, which include higher salaries for this type of work.

The growing need for long-term care creates additional costs in the Western Balkans, which represents an increasing challenge both from the point of view of the personal income of citizens and from the perspective of public finances. It is quite certain that the majority of citizens in the Region cannot independently finance long-term care, nor will economic growth in the foreseeable future enable an increase in personal income that would contribute to a significant change in these circumstances. Therefore, pressure on public expenditures, already marked by the growth of the budget deficit in the Region, is inevitable. It is obvious that long-term care policies in the Western Balkans should be especially directed to the effectiveness of support programmes, which, due to lower economic development, should be even more pronounced than is the case in more affluent EU countries.

The effectiveness of long-term care could also be improved by adequate planning. In the largest part of the Region, a uniform mechanism for collecting data on long-term care beneficiaries, types of support and costs incurred have not been established. The establishment of such a mechanism would enable data processing, monitoring and evaluation of long-term care as a basis for adequate planning at the macro level. At the moment, it is

almost impossible to review the total expenditures for long-term care because the records are partial and often unreliable. It should be taken into account that the administrative definition of long-term care is imperative for establishing appropriate planning.

There is no doubt that the growing need for long-term care encourages the need to formulate new long-term care financing models in the Western Balkans. Similar circumstances are present in other European countries. Germany has introduced a special type of social insurance for long-term care and this is an option that should be considered in the Western Balkans too. On the one hand, it is difficult to expect that citizens with functional difficulties will have sufficient income to cover the costs of long-term care. On the other hand, with adequate coverage, it is quite possible that public costs for long-term care would reach the point of unsustainability in the near future. Also, further plans could be directed towards the establishment of special-purpose public funds for long-term care that would be financed from various sources. In any case, long-term care policies in the Region should contain a component for establishing a uniform fiscal area dedicated to this purpose.

The availability of formal long-term care services in the Western Balkans is extremely low. Residential services, often considered a traditionally widespread form of long-term care in the Region, are in fact poorly represented compared to the EU. The availability of services in the community, in the form of day centres where various activities are carried out during a certain part of the day, can be assessed as insufficient compared to the needs. However, it seems that in relation to the needs, the services provided in beneficiaries' homes are the least available.

3. WHAT ARE THE LONG-TERM CARE NEEDS OF OLDER PERSONS AND PERSONS WITH DISABILITIES?

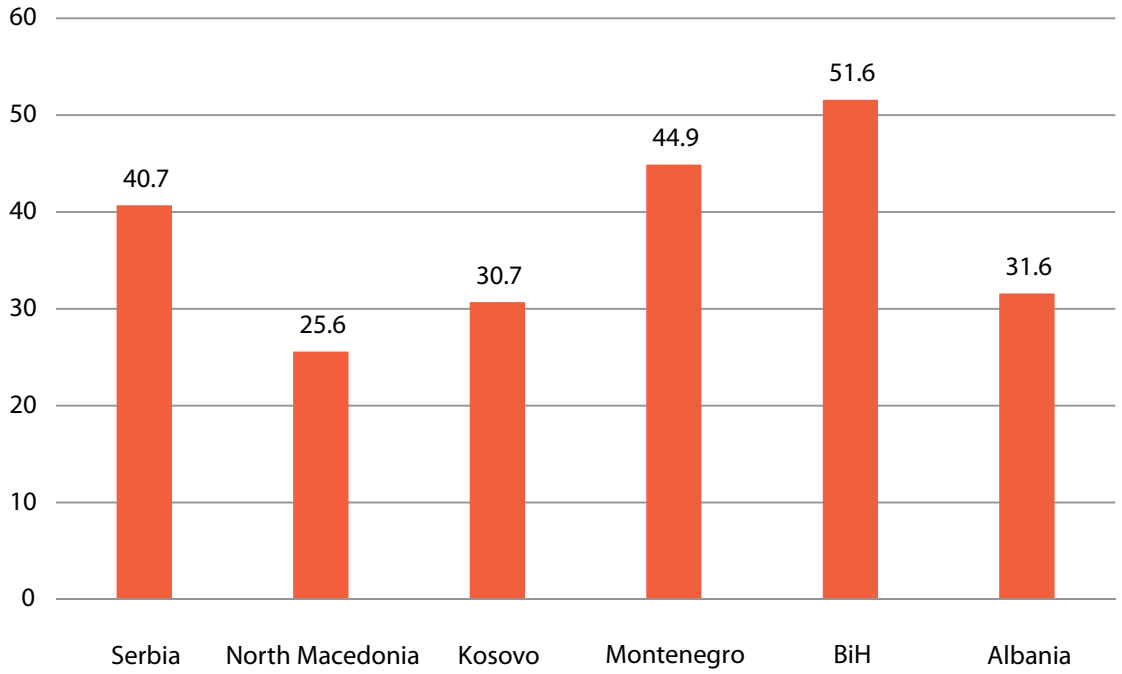
In addition to the personal companion service, long-term care is an important service that can improve the life of PWDs, regardless of their age. Therefore, an insight into the characteristics of this part of the population leads to a closer understanding of the long-term care demand. The United Nations (UN) Convention defines persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". However, long-term care has a somewhat narrower scope and is aimed at people who, due to difficulties caused by the conditions listed in the definition of persons with disabilities, are unable to perform activities of daily living on their own. Data on the number of persons with disabilities, which were collected by censuses in the Western Balkans, provide an insight into the extent of this population precisely on the basis of the census question related to difficulties in functioning. Differences in the share of people with disabilities within the region largely coincide with data on the ageing of the population.

Since ageing is an additional risk for the reduction of functional abilities, it is quite expected that environments with a larger share of older population also have a larger share of citizens with difficulties in performing activities of daily living. Disaggregated data from the census show that the proportion of the population with functional limitations is higher in rural areas than in urban ones.

More recent research shows that the share of people over 65 years old in the Western Balkans who stated that they have greater difficulties in their daily functioning differs significantly between countries. According to the findings of the regional research conducted by SeConS in 2021[16], North Macedonia has the fewest older people who experience greater 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. Although it is a subjective experience of the complexity of the difficulties they are facing, these findings nevertheless bring us closer to the knowledge of the need for additional support when facing functional limitations. This is especially important in the older age group, given their Healthy Life Expectancy.

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

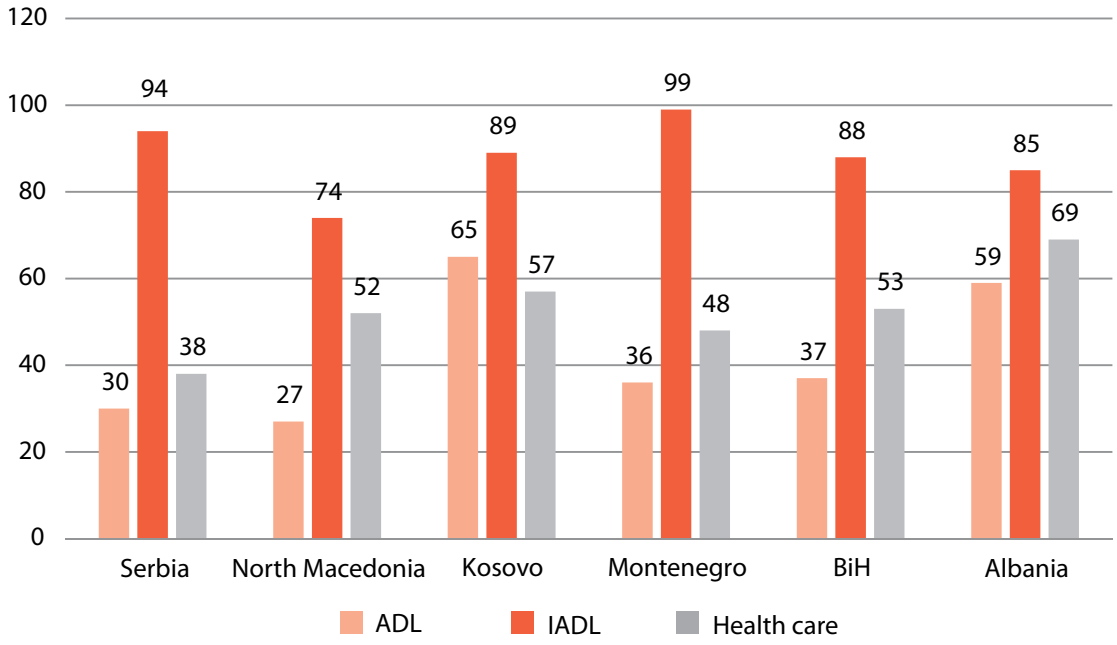
Graph 1: Share of persons older than 65 with greater difficulties in performing activities of daily living (%)



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

Western Balkans people over the age of 65, who rate their difficulties in daily functioning as great, mostly face challenges when performing instrumental activities of daily living. The greatest needs in instrumental activities of daily living were expressed by older persons in Montenegro – almost all respondents who have greater difficulties in daily functioning pointed out that these difficulties are related to instrumental activities. When talking about health care, respondents from Albania said they faced the greatest difficulties, and those in Serbia had the least.

Graph 2: Groups of activities in which the citizens of the Western Balkans over 65 face greater difficulties (%)



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

The frequency of long-term restrictions increases with age and decreases with income growth, both in the Western Balkans and in the EU. Functional limitations have a clear age-related pattern. People in older age groups are more likely to report functional limitations compared to younger age groups. The difference in the share of the population with limitations in performing activities of daily living between the age group 16 to 24 years and the group aged 85 and older in the Western Balkans ranged from 58,3 percent in Serbia to 81% in Albania in 2020. This difference in the EU-27 was around 65 percent. The prevalence of functional limitations was highest in the lowest income group and progressively decreased with increasing income.

Slightly less than half of the EU population, aged 65 and older, reported limitations in performing household activities.[17] More than 50 percent of older persons in 12 EU Member States[18] reported limitations in performing household activities. The highest rates were recorded in Lithuania and Romania i.e. 67 and 79.6 percent respectively. Rates for older persons reporting difficulties in performing personal care or household activities differed between the two genders, with older women showing higher rates than older men in all EU Member States. Older women reported difficulties in performing personal care activities in a proportion of 27.5%, while the corresponding rate for older men was 18.7%. In Serbia, 53.9% of citizens over the age of 65 declared that they have limitations in performing household activities, with 31.5% of older persons having more serious limitations. Just like in the

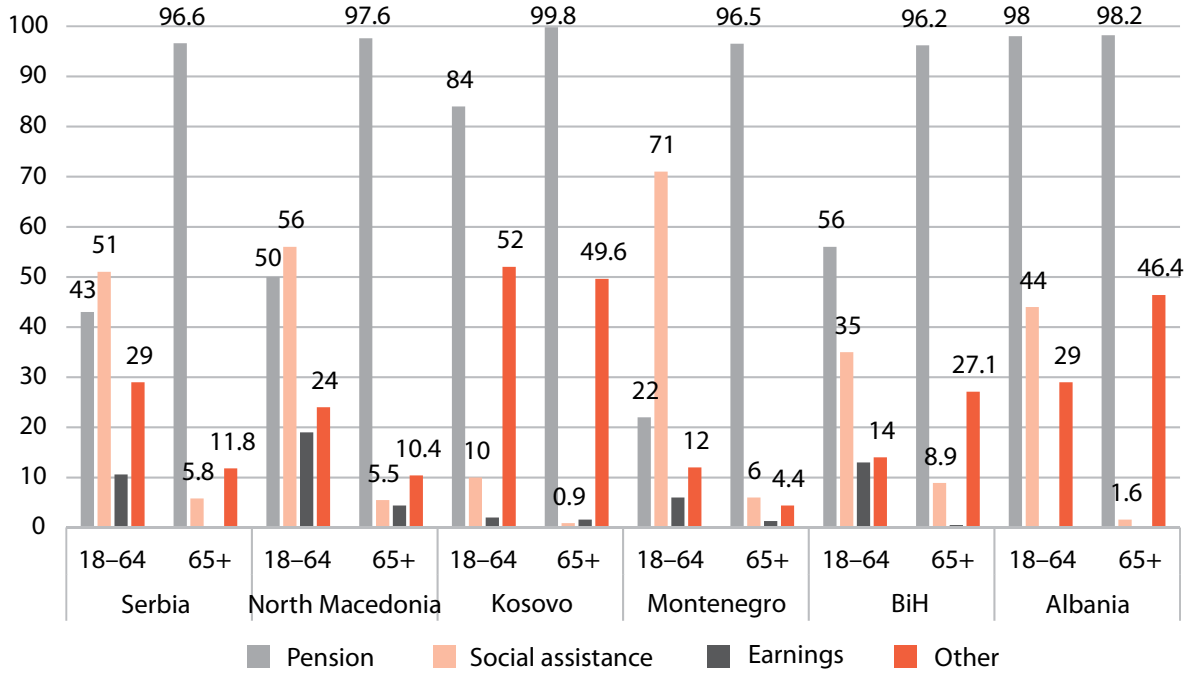
17 Eurostat, HLTH_EHIS_HA1E.

18 For example, Greece, Poland, Cyprus, Bulgaria, The Netherlands, Czech Republic, Lithuania, Romania.

EU, there is a higher rate of women who noted these difficulties, 37.7% of them, than men, where this rate was 23.3 percent.

At least 96% of older persons who declared that they have greater difficulties in performing activities of daily living, in the entire Western Balkans region, receive a pension as their main source of income. Pensions are the dominant source of income for people with disabilities in Kosovo, in Albania, which is probably a consequence of the wide coverage of the disability pension programme, and in Bosnia and Herzegovina, where during and after the war in the 1990s, the war disability pension programme was highly developed. In the entire region, except Kosovo, a significant proportion of adults with severe disabilities derive their income mainly from social benefits, which is especially related to Montenegro. Other sources of income, which primarily include rent income, financial assistance from relatives, etc. play an important role in the incomes of adults with difficulties in Albania and Kosovo where multi-member households have persisted and where extensive diaspora takes responsibility for financial support of family members in their homeland. Other incomes are still partly important in Serbia and North Macedonia. Earnings are rarely the dominant source of income for adult persons with disabilities. Earnings are somewhat more prevalent as the income of persons with disabilities in North Macedonia, followed by Bosnia and Herzegovina and Serbia. Older persons with greater difficulties in performing the activities of daily living, in addition to pensions, obtain most of their income from other sources, especially in Kosovo and Albania.

Graph 3: Types of income of persons with greater difficulties in performing the activities of daily living (%)



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

4. WHAT ARE THE MAIN FEATURES OF LONG-TERM CARE FOR ADULTS AND OLDER PERSONS IN THE WESTERN BALKANS REGION?

Long-term care in the Western Balkans is not legally regulated as a clearly defined activity of public importance, but its elements are found in several different systems, primarily in social welfare and health care. Social welfare can be considered primary in the field of long-term care in the Region due to the absence of a uniform system that defines the scope and content of this activity. In addition, social welfare often, due to lack of family care, acts as a substitute for the family. However, from the point of view of long-term care, there are two models in the Western Balkans region. Albania and Kosovo apply relatively consistently the principle of personal and family responsibility with the partial provision of services that contribute to long-term care from public funds. Contrary to that, in North Macedonia, Serbia, Montenegro and Bosnia and Herzegovina, although the regulations related to social welfare establish principles according to which citizens primarily take care of themselves and their family members, an exception is made in the case of long-term care. Namely, in the process of realizing the right to financial allowances for custodial care and assistance, the right to long-term care from public funds is implicitly recognized because this type of support is provided without prior checking of the financial condition of the beneficiary and the availability of family support.

Health care, although an integral element of long-term care, plays the role of a complementary activity rather than the source of long-term care. People in need of support for performing activities of daily living, as a rule, have poor health which is the cause of the need for long-term care. However, the health care systems in the Western Balkans are focused primarily on the treatment of acute states of the underlying chronic disease, which is not the primary goal of long-term care. A key element of long-term care within health care is home treatment services, especially those aimed at dealing with underlying chronic diseases (often more than one) and preventing them from worsening or developing complications. Health care is somewhat closer to long-term care in the domain of managing chronic health problems, but even then the focus is on maintaining the patient's current condition rather than dealing with the consequences of dysfunctionalities.

4.1 Regulating long-term care

Measures and services aimed at supporting people unable to perform activities of daily living on their own are primarily regulated at the central level in the Western Balkans region. Montenegro, Kosovo and Northern Macedonia have umbrella regulations at the central level for both social welfare and health care. On the other hand, Serbia regulates health care at the central level, while social welfare rights are determined by a single regulation for the entire country, but it is up to local authorities to further regulate the conditions for exercising the right to provide services in the community from the local self-governments funds. The regulation of long-term care in Bosnia and Herzegovina is subordinated to a complex state-administrative system. EU Member States have different long-term care regulation practices. Although in most Member States the ministries in charge of health and/or social affairs are responsible for regulating the provision of long-term care services, some responsibilities may be delegated to other authorities or insurance funds.[19]

Assessment of beneficiaries' needs is organised at the central level throughout the Region. Even in Bosnia and Herzegovina, characterized by scattered jurisdictions, needs assessment is centralized. However, what is characteristic of the entire Region and represents one of the biggest challenges is the separation of the assessment of the needs for health care and social services and the lack of coordination of these systems during the assessment.

About half of the EU Member States regulate standardized needs assessment at the national level.[20] In the remaining EU countries, needs assessment methodology may differ at the regional and even local level, as well as between sectors and sources of financing. A needs assessment can be performed by different professions (eg. nurses, doctors, specialized health personnel, social workers), sometimes organised as multidisciplinary teams.

The quality of long-term care in the Western Balkans is based on developed standards and control of their implementation. Health service standards have been developed for the entire Region and their application and improvement have a long tradition and developed procedures. The standards for the provision of social services are somewhat recent, and their implementation is still not fully established in practice. Serbia, Montenegro, North Macedonia and Albania have established standards for social care service providers and staff, while quality is additionally ensured by profession-

The first level of provision of standards implementation is based on licensing of organisations and staff in charge of social services provision as well as on accreditation of professional training programmes.

The second level of standards implementation is ensured through inspection supervision and the supervision of professional work.

19 For example, Austria, Belgium, Bulgaria, Czech Republic, Germany, Estonia, Finland, France, Romania, Sweden.

20 SCP & DG EMPL, 2021.

al training programme standards. In all four countries, inspection is organised at the central level. Due to insufficient human resources for inspection supervision, verification is focused on the application of standards mainly only for residential services. The specific feature of the standards related to the quality of social services in Kosovo is that the licensing procedure and quality standards apply only to providers of social services that do not belong to the public sector[21] while the quality system of public service providers remains unregulated. However, the competent ministry is obliged to supervise the work of all social service providers, regardless of their founder.

The most common approach to quality monitoring in EU countries[22] is based on a set of predetermined standards and requirements.[23] The standards mainly regulate residential care and in some, very rare, cases, home care.[24] The process of assessing compliance with standards usually involves on-site inspections[25], however, some national reports reflect problems arising from limited resources, lack of qualified inspectors and lack of process transparency. Differences can also appear between the social and health sectors. In some countries, the health sector has clear and well-established standards[26] compared to the social sector. It should be noted that standards can be established at the national level, but also by regions, provinces or municipalities[27] which may lead to differences within the national context.

Public and private service providers equally perform activities in the field of social welfare and health care, and civil society organisations play an important role in providing social services in the community. However, when it comes to access to public finances, the circumstances are quite different. Public health insurance funds in the Western Balkans are mainly financed by public health institutions. Public institutions are financed from state funds based on the obligations of the founders, and from health insurance funds based on the services they provide. Everywhere in the Region, there is a foreseen possibility of financing health services provided by entities outside the public sector, but this practice is rather the exception than the rule. Social services provided at home and in the community are financed from public funds, regardless of whether the service providers belong to the public or private sector. However, the financing of services provided by private service providers or non-governmental organisations is often unstable, limited by time or project-organised, which jeopardizes the planning and development of those organisations. Unlike others in the Region, Albania divides

21 Administrative instruction no. 02/2020 for licencing non-governmental organisations and private legal persons which provide social and family services, indicated according to the Manual for licencing non-governmental organisations and other private legal entities which provide social and family services, 2021.

22 For example, Czech Republic, Germany, Spain, Finland, Ireland, Liechtenstein, Lithuania, Latvia, The Netherlands, Poland, Portugal, Romania, Slovenia, Slovakia, Great Britain.

23 Spasova et. al, 2018.

24 Ibid.

25 For example, Czech Republic, Ireland, Lithuania, Portugal, Slovenia.

26 For example, Portugal, Slovenia.

27 For example, Austria, Czech Republic, Italy.

social service providers into profit and non-profit ones, whereby profit organisations cannot use public funds. In the EU, there is also a pluralization of service providers, and the provision of care is offered and organised by both public and private institutions.

4.2 Long-term care management

Long-term care management in the Western Balkans is mainly decentralized. Central authorities assume responsibility for financial allowances and the management of health services, while the management of social welfare services is divided in various ways between local and central levels. Big differences between the capacities of local authorities in managing long-term care are a common characteristic in the Region. Uneven economic development between local administrative units, in the context of long-term care, is evident throughout the Region, especially in Montenegro and Albania. On the other hand, the importance of decision-making by local stakeholders is noticeable in systems with a slightly higher level of decentralization such as FBiH and Serbia, and to a lesser extent Albania and North Macedonia. Also, the lack of coordination between the health and social care systems in long-term care provision can be classified within common characteristics. These two systems, as a rule, operate completely separately, primarily due to different sources of financing and the lack of administrative procedures that, guided by the expected outcome, would connect them into one single entity. At the same time, the policies that are established, starting from the highest levels of government to local authorities, are mostly limited by sectors. Such circumstances are evident even where social and health care are organisationally placed in the same ministries, as is the case in Albania, Bosnia and Herzegovina and Kosovo. The horizontal division between the health and social sectors is also accompanied in many EU countries by a vertical division of responsibilities between different institutional levels: national, regional and local.[28] Only a few EU countries[29] organise the system in a way that horizontally integrates health care and social welfare.

Decentralization in the Western Balkans should have a significant impact on the availability of services that contribute to long-term care. On the one hand, getting closer to the beneficiary is certain to have a positive impact on the availability of services. It is hard to imagine that services within a community can be adequately organised from a central level and at the same time keep their focus on the needs of the beneficiaries. On the other hand, the different sizes of local self-governments and their general fragmentation call into question local capacities for organising and provision of long-term care services. From the point of view of financing services, the weaknesses of the economic development of individual local communities may be corrected with support from the central level. Almost everywhere in the Region, there are programmes that financially support local governments in providing long-term care services. The effects of these programmes have not yet been fully evaluated, but there is no doubt that a significant proportion of local communities do not have the financial strength to respond to the needs of citizens. It is very likely that an adequate solution should be sought

28 SCP & DG EMPL, 2021.

29 For example, Denmark, Ireland, Portugal.

at the administrative level between the central and local authorities. However, experiences from Bosnia and Herzegovina, where management of long-term care measures and services is at the cantonal level, indicate that not even the middle administrative level ensures adequate management. Based on the presented challenges and experiences, long-term carepolicies, in terms of availability, could be directed towards financing from the local level with mandatory support of the central government and towards middle government-level management but rights in the field of long-term care would be established at the state level. Maximum efficiency and effectiveness would be ensured this way while achieving the equality of all citizens.

4.3 Long-term care financing

Long-term care in the Western Balkans is financed from three conventional sources of funds: taxes, insurance and citizens' own money. However, most often, funds from all three sources participate simultaneously in the financing of long-term care, but in different proportions. Funds from general taxation, primarily from central budgets, play a dominant role in financing long-term care services. It is important to note that the financing of long-term care has an increasing share in the public expenditures of local authorities. Previous experiences in the Western Balkans have shown that the availability of social welfare services in the local community largely depends on funds from the central budgets. Compulsory insurance funds are mainly directed at providing health care, while private insurance is still not a widespread practice. Citizens throughout the Region directly participate with their own money in the provision of both health and social welfare services. Public financing of long-term care services and financial benefits in the EU depends on the needs of the beneficiaries, their income and financial status, as well as the availability of family support.[30] Most of these expenditures in the EU are financed by general taxation. In almost all EU countries, beneficiary is obliged to participate in the costs of long-term care services. EU members, within the framework of the hybrid approach, often combine different models of financing long-term care services in order to ensure the sustainability of the system through the efficient organisation of risk sharing.

The budgets of the local administrative units in the Region primarily finance day care and home services from their revenues.

30 Spasova et. al, 2018.

5. 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. Furthermore, services can be classified into residential services, which imply 24-hour support, seven days a week, daily services and services in the beneficiaries' homes. The other two types of services are provided with different dynamics in accordance with the needs of the beneficiaries but are primarily subject to available local capacities.

The procedure for using measures and services that contribute to formal long-term care is strictly divided between social welfare and health care throughout the Region. Health services are used based on the examination of doctors from the network of local health centres developed throughout the region, as a rule, at the municipal level. The procedure for using services and financial benefits from the social welfare system is implemented everywhere in the Region, except in Albania, through social work centres, which are, established as kind of referral bodies, as a rule, for each local self-government. In Albania, this procedure is implemented through the municipal social worker, and the final decision is made by the local committee.

EU Member States also provide formal long-term care through services and financial allowances, or a combination of these two types of support.[31] Services usually include home care or placement in residential institutions, but may also include other needs such as home adaptations or the purchase of technical devices.

5.1 Residential services

Residential social welfare services[32] **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

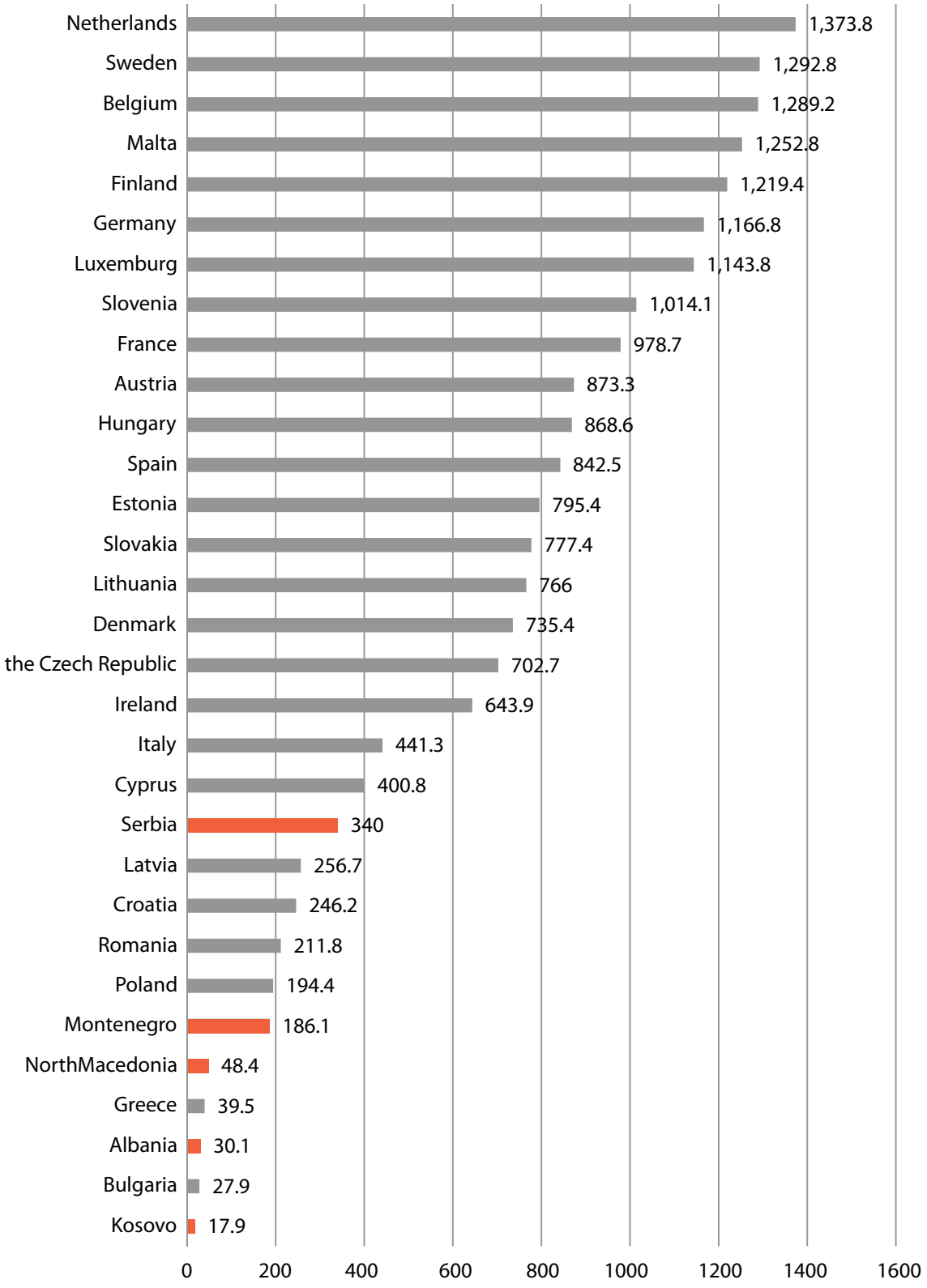
31 SCP & DG EMPL, 2021.

32 "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).

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. Health care services from compulsory health insurance funds are available only in public accommodation facilities, while private facilities rely on the network of local health centres and more often on private health services, the provision of which is an additional burden on the beneficiaries' income. Palliative care in accommodation facilities is more of a situational reality than an organised type of support, so there was no adequate equipment and training for employees. Only Montenegro has an organisational unit for palliative care in an accommodation facility, which is equipped and organised in an appropriate manner. An example of good practice is the Gerontology Institute of North Macedonia, which, although a specialized hospital, integrates geriatric, long-term and palliative care. It is obvious that residential services in the Region need to be redesigned in order to take into account the specific needs for 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, and only Bulgaria has fewer capacities than Albania. Montenegro and North Macedonia have a somewhat higher number of beds in residential institutions per 100,000 inhabitants. According to these indicators, Serbia stands out a bit from the rest of the Region and has greater capacities than 10 European countries, which is a consequence of the expansion of the private sector in this area. The private sector of residential services is also becoming stronger in North Macedonia, while public capacities remain limited despite accommodation organisations managed by the national pension insurance fund, but outside the formal system of long-term care services. In recent years, Montenegro has doubled the public capacity for providing residential services, while the private initiative has remained neglected. The current capacities exceed the indicated needs of the beneficiaries, but a clearer market reaction can be expected in the upcoming period.

Graph 4: Residential services capacities – number of beds per 100.000 inhabitants (2020)



Source: Eurostat, HLTH_RS_BDLTC;

The data of the ministry in charge of social welfare were used for North Macedonia;

The data from the Institute of social and child protection were used for Montenegro;

The demand for residential services is increasing along with the development of capacities in private institutions for the placement of older persons. Nevertheless, there are still citizens whose need for this service is not fulfilled, which most often refers to accommodation in public institutions due to lower prices, although there are waiting in some private institutions as well. In Serbia, there were four times more people on waiting lists in December 2019 than in 2017.[33] Waiting lists in homes that mainly provide services for older persons have been decreasing in previous years due to the expansion of the private sector. However, the number of beneficiaries waiting for placement in institutions for people with disabilities is continuously growing, and the capacities of these organisations, which are exclusively established by the state, have not changed for several decades. Very few beneficiaries are waiting for the provision of residential services in Montenegro, and capacity occupancy in 2021 was 82%[34]. Namely, the newly founded institutions are in cities where have been no adequate capacities until now, and for the first time, organisational units for palliative care were designed in the institutions. The capacities of public institutions for the placement of older persons in Albania, where the service is not charged or is charged in the amount of 40% of the pension, do not meet the current needs. Of the 120 applications for services in residential facilities in 2020, only 42 were accepted and the remaining 78 were placed on a waiting list.[35]. At the same time, the capacity occupancy of private institutions for older persons was 93%. More than half of the residential institutions, which especially refers to private organisations, are concentrated in the region of the capital, Tirana. The capacities of private institutions for housing older persons in North Macedonia have almost tripled compared to 2015.[36] The number of beneficiaries in public institutions has been decreasing in previous years, while the number of those in private organisations is increasing.[37] Data for Kosovo are not publicly available.

Giving priority in financing to public service providers affects the increased demand for residential services in public institutions. Although in almost all parts of the Region, apart from Albania, the legislative framework enables the financing of accommodation services from public funds provided by private profit organisations, this practice is extremely rare. Accommodation services provided by private organisations have been financed in Serbia since 2017, but the number of beneficiaries is exceptionally small, and the entire procedure is very difficult.

The majority of Western Balkans citizens, who have declared that they have greater difficulties in performing activities of daily living, believe that community services are a more appropriate type of service for them compared to residential care services.[38]

33 Miloradović, Milojević, Ković, Todorović, Vračević, 2021.

34 Institute for Social and Child Welfare, 2021; Public institution "Komanski most", 2022.

35 International Labour Organisation (ILO), 2022.

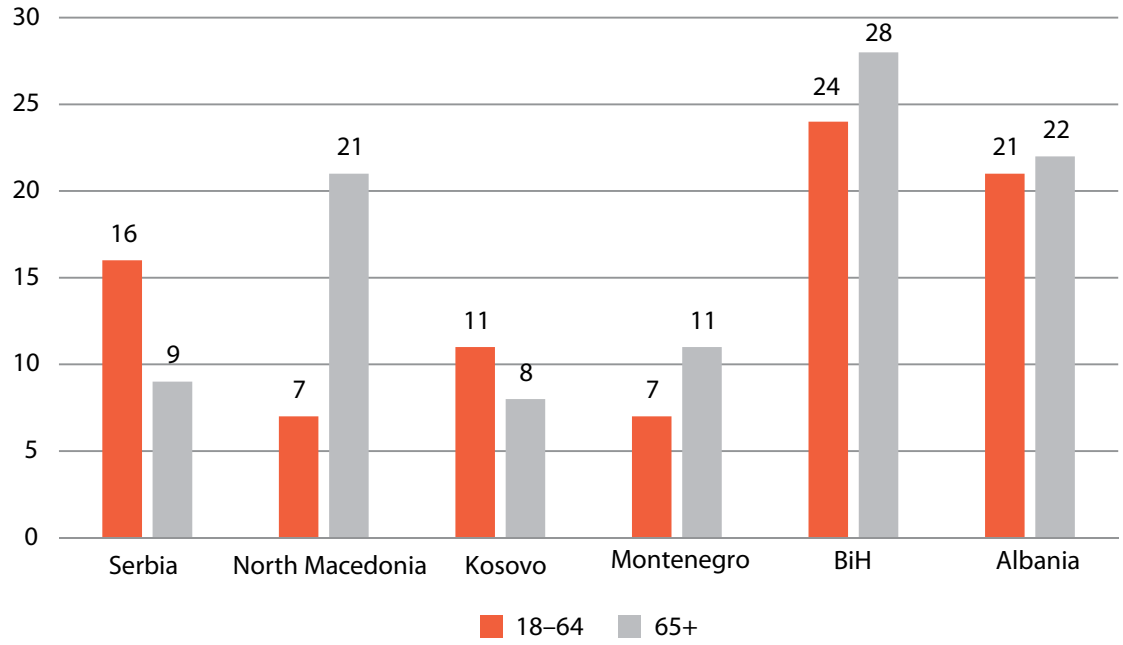
36 Republic of North Macedonia, Ministry of labour and social policy, (s.a.).

37 State Statistical Office, Republic of North Macedonia, 2020.

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

Residential services are the most acceptable for residents of Albania and Bosnia and Herzegovina, where one-fifth and one-fourth of respondents accept this type of support. The share of citizens of Kosovo and Montenegro, needing long-term care, who prefer residential services range from 7 to 11 percent.

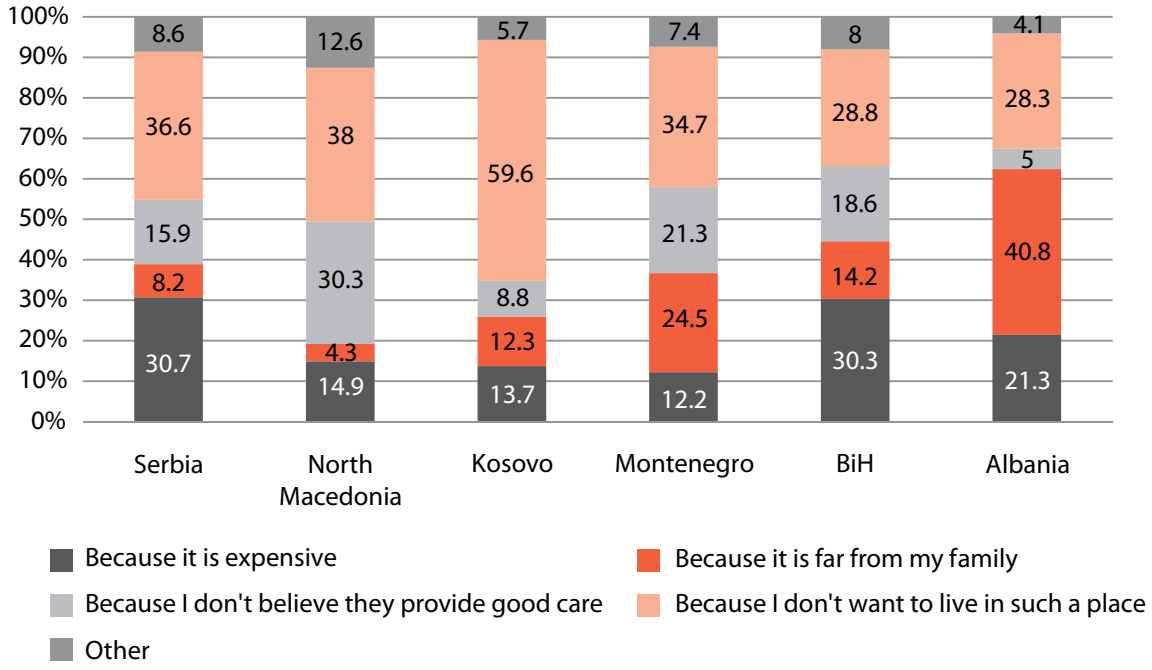
Graph 5: Share of Western Balkans citizens with greater difficulties in performing their activities of daily living who have declared readiness to use residential services (%)



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

The reasons why the citizens from the Region do not wish to use the placement services in an institution differ, but the common feature is the subjective resistance to the institutional model of long-term care based on prejudices related to residential placement. As many as 59.6% of respondents over the age of 65 in Kosovo pointed out that they do not want to live in such a place, while in Serbia, Montenegro and North Macedonia, about two-thirds of the respondents provided the same answer. The price of the service is the most important reason for respondents from the same age category in Bosnia and Herzegovina, but in Serbia, it is indicated as the second most important reason for a negative attitude towards the institutional placement service. Distance from family is the most important reason for older persons respondents from Albania and the second most important reason for respondents from Montenegro. Distrust of people older than 65 in placement service providers is most evident in North Macedonia, where about one-third of the respondents do not trust the quality of the service, while this attitude is shared by one-fifth of the respondents in Montenegro. For PWDs, the same as for older persons, personal attitudes towards placement are the most dominant reason. However, for PWDs, the distance from family is somewhat more significant than for older persons.

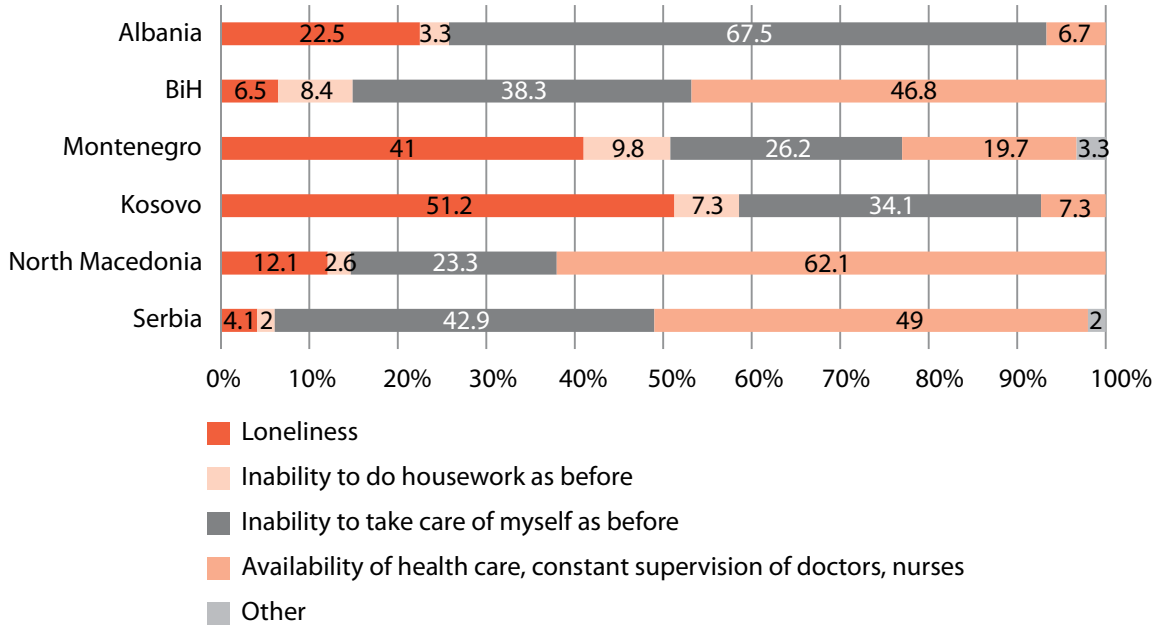
Graph 6: Reasons why the respondents older than 65 would not want to use the placement service (%)



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

The reasons why older citizens would still decide to use the institutional placement service greatly differ across the Region, but facing the reduced possibility of self-care is important to everyone. 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. Older citizens of Serbia and Montenegro who reported greater difficulties in performing daily activities are more inclined to be placed in public institutions, while in North Macedonia they prefer private providers of this service. In the rest of the Region, the division of residential services according to the founder has no clear prevalence.

Graph 7: Motivation of citizens older than 65 for use of the placement service (%)



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

5.1.1 Family accommodation

Family accommodation (foster care) is a special form of residential service that is part of the social welfare system in the Western Balkans region, except in Albania and Kosovo. This service was initially developed as an alternative to institutional placement of children but was later applied as a form of support for adults and older persons, so that, in addition to various functional limitations, they could continue living in a family environment and within the community. This type of care does not require special qualifications, protection, participation of the community, as well as the use of its resources. The service of family accommodation is primarily provided by relatives, when it is in line with the best interests of the beneficiary, or by another person who meets the relevant standards.

Expenditures for the provision of family accommodation services consist of remuneration for work and remuneration for the support of the beneficiary. The closest family members who, in accordance with the regulations governing family relations, are obliged to support the beneficiary, do not receive compensation for work in providing the family accommodation service, so the costs, in this case, are limited to compensation for supporting the beneficiary. As with placement in an institution, the costs of family accommodation are primarily borne by the beneficiary. Public funds are allocated for this service according to different national models. According to the national legislative framework, the fees for family accommodation are regulated in different ways, but there are no major deviations in relation to average salaries. Often, this fee is determined separately in a basic and increased amount, intended for the provision of a service requiring more intensive care.

Table 1: Share of family accommodation fees in average salary

Fee	BiH		Montenegro	N. Macedonia	Serbia
	FBiH	RS			
For the beneficiary's expenses	30%–50%	45%–55%	40%	60%	40%
For the service provider's work	15%–30%	25%	10%–20%	60%	20%
Total	45%–80%	70%–80%	50%–70%	120%	60%

Source: Calculations done by the authors for the study based on publicly available data

Contrary to the developed legislative framework in the field of family accommodation, this type of support for adults and older persons does not have a significant share in long-term care. In 2021, family accommodation in Serbia was used by 16 adults[39] and 10 in BiH[40] per 100.000 persons of legal age. However, in both mentioned countries, about one half of beneficiaries belong to the age category of young people who very likely used this service as children and then continued with this type of support until they became independent. North Macedonia and Montenegro have a negligible number of beneficiaries of this service. In 2021, family accommodation in North Macedonia was used by only 28[41] beneficiaries, of whom only three were older than 65, while in Montenegro in 2019, eight[42] older citizens were placed with other families.

People over 65 in the Western Balkans rarely consider family accommodation as a way to meet the need for long-term care[43]. The largest number of respondents pointed out that they would not consider family accommodation as a form of support. 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, the most undecided ones are older persons from Albania and Kosovo, 34,5% and 31,5%, respectively, who could not say whether they would consider this type of accommodation. Compared to other parts of the Region, the North Macedonia older persons display the most affirmative attitude towards family accommodation – slightly more than a fifth of older persons indicated that they would consider family accommodation as a type of service. Those who said they would consider family accommodation cited the inability to take care of themselves as before and loneliness as their main reasons. Looking at the entire Region, the inability to take care of themselves as before is the main reason for opting for this type of service.

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

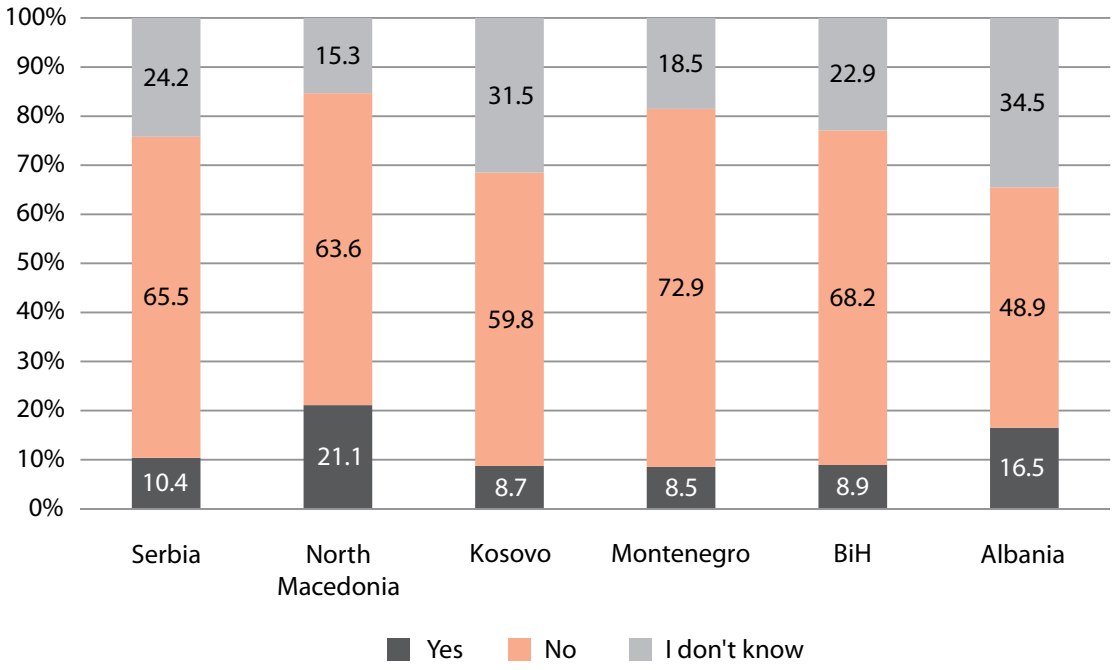
40 Agency for Statistics of Bosnia and Herzegovina, 2021.

41 State Statistical Office of the Republic of North Macedonia, 2020.

42 Institute for Social and Child Welfare, 2019.

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

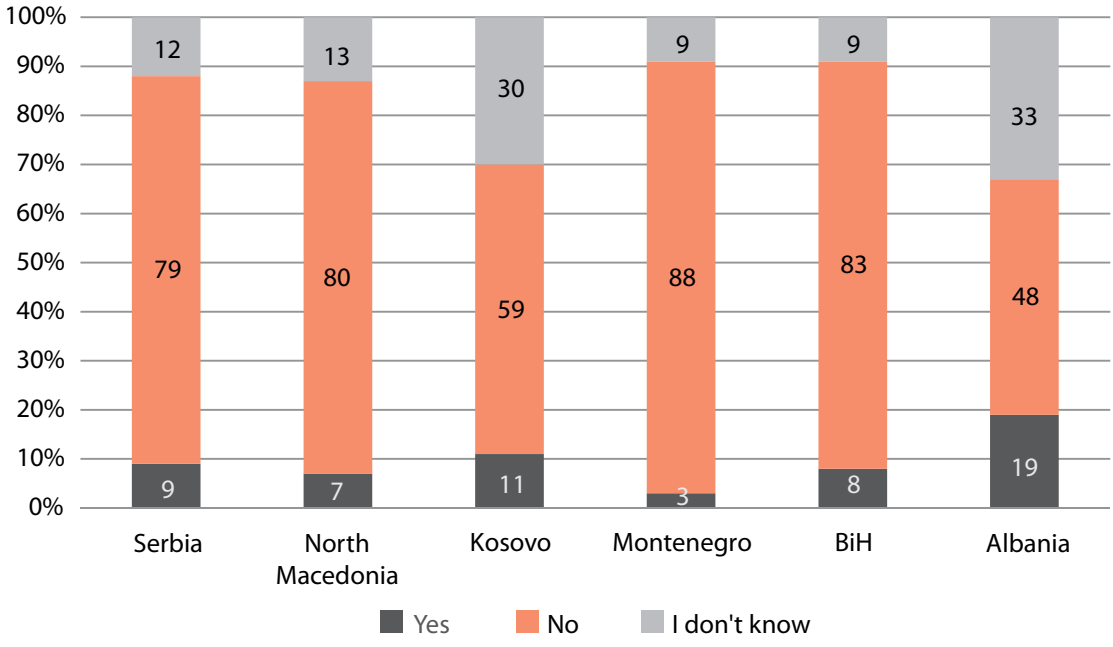
Graph 8: Readiness to provide family accommodation service, 65+ (%)



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. 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.

Graph 9: Readiness to provide family accommodation service, PWD (%)



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

5.2 Home services

Home assistance services can be organised within the social welfare or health care system. As a rule, these services are organised within the framework of social welfare and include support in performing activities of daily living, care and supervision, in conditions when family support is insufficient or unavailable. Home care, as a typical health-related activity, implies acute medical care aimed at recuperating, which is often performed as an extension of hospital treatment. In addition to the health services provided at home, we should also add visiting services, the work of which is often combined and even regarded as the same as home care. Attempts to unite the content of this service, provided in the beneficiary's home, have been noted almost throughout the Region, but these aspirations have been limited to project activities due to administrative and financial obstacles. The practice of home assistance services in the Western Balkans is limited to providing support in performing activities of daily living. Support in performing instrumental activities of daily living is very rare, primarily because it requires the engagement of significant resources.

The home assistance service is not uniform in nature, since it is adapted to the individual needs of the beneficiary in specific living circumstances. This type of service includes providing food, medicine or other necessities for the beneficiary, maintaining personal hygiene, psycho-social support and help with meeting other daily needs. Home assistance makes its full contribution, especially in terms of efficiency, when combined with other community services and informal care. However, as these services are organised at the municipal level throughout the Western Balkans, different practices have been developed which, in addition to the needs of the beneficiaries, are subject to local capacities. Home assistance varies in content, intensity and scope in local communities. At the same time, the characteristics of the service are influenced by the informal market. Namely, due to the weakness of the institutional framework, beneficiaries often independently contract services with informal care providers, and the provision of such contracted services remains beyond the reach of official records and supervision.

The most prominent is the need of the citizens of the Region for services provided at home. However, although the official policies in the Region emphasize the development of home assistance as a priority, this service is significantly available only in Serbia, while it is provided sporadically in other parts of the Region. Even in Serbia, where the home assistance service is the most widespread in the Western Balkans, this type of support is used by less than 1.5% of PWDs and about eight percent of people over the age of 65, who reported severe limitations in performing activities of daily living.[44] It remains to be seen in the upcoming period to what extent the formulated public policies in the Region that emphasize the importance of this type of service will contribute to its increasing availability.

Even though public policies in the Region give priority to home assistance, these services generally do not have sufficient capacities in relation to needs. Available reports indicate that in most of the Western Balkans region, the provision of home assistance services

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

is predominantly based on the project activities of national and international non-governmental and humanitarian organisations. 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. Home assistance in North Macedonia is just beginning[45] and according to data from the Registry of Licensed Service Providers[46] only one organisation has obtained a license to provide this service. It is similar in Albania, where only one municipality provides home assistance for 20 beneficiaries and two private providers are offering this service for 35 beneficiaries.[47] The pronounced lack of public support for home assistance in Kosovo is mitigated by the work of non-governmental and humanitarian organisations. According to the data of the Agency for Statistics of Bosnia and Herzegovina, in 2020, approximately 13 beneficiaries out of 100.000 adult citizens used home assistance services[48]. In Montenegro, this service was available in 15 out of 25 municipalities in 2018[49]. Although there is only one licensed home assistance provider in Montenegro, according to the findings of the Mapping, a total of 19 organisations provide this service. The home assistance service is the most widespread in Serbia, where according to the data of the competent ministry, as many as 111[50] organisations in Serbia were licensed to provide this service in 2021.

The market for home assistance services in the Western Balkans is, quite obviously, still not sufficiently developed. Although all demand 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, due to low income, are unable to afford professional services. Public funds allocated for this purpose, judging by the number of beneficiaries, are insufficient. Short-term demand is fueled by humanitarian and international funds that cause instability by creating unsustainable expectations among all stakeholders. Additional challenges are 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 control 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 procedure, which ensures the implementation of standards for the provision of home assistance services in the entire Region, except in Serbia, is rather difficult. 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.

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

46 Republic of North Macedonia, Ministry of Labour and Social Policy (s.a.-a).

47 International Labour Organisation, 2022.

48 Agency for Statistics of Bosnia and Herzegovina, 2021.

49 Institute for Social and Child Welfare, 2019.

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

The provision of home services as a form of long-term care varies significantly between EU Member States. According to the results of the EHIS survey from 2019[51], home assistance services are used on average by about 29% of citizens with greater difficulties in performing personal care or household activities. While this share in Belgium, Denmark and the Netherlands exceeds 50 percent, in Romania only 4.7% of older persons with greater difficulties in daily functioning have used home care. According to the same source, in Serbia, where home assistance is the most widespread in the Western Balkans, this share was 12.9%, which is more than in four EU countries. Although home assistance is a priority in the public policies of most EU countries, more than one third of households in need of long-term care do not use home assistance for financial reasons.[52]

5.3 Day services within the community

Day services in the community are generally provided in day centres as full-day or half--day stay services. These services provide daily care and supervision, rehabilitation, and organisation of free time. Often, these services can include various social and recreational activities, which contributes to the prevention of the development of various long-term care needs. In this way, the quality of life of beneficiaries in their own social environment is also improved. An important component of this service is the opportunity it gives to members of the beneficiary's family to engage in work and other activities, thus contributing to the improvement of social and economic living conditions. The providers of these services are mostly non-governmental organisations entirely dependent on the availability of donor funds, including grants from the competent ministry. The capacities of day care centres managed by NGOs are rather small, but they meet the prescribed standards. In addition, there are private day care centres in urban areas, but the quality of these services is not regulated.

The frequency of service provision varies due to the influence of several factors. The individual needs of beneficiaries certainly have a decisive role, but they are closely related to the availability of other services and informal care with which daily services have a complementary relationship. Financial and professional capacities in the local community also influence the frequency of service provision. Furthermore, taking into account that the provision of the service is related to a specific location, the distance of the beneficiary from the day centre and the possibility of transportation are influencing the availability and frequency of service provision.

Although several models of day services have been developed across the Region, they are most often organised as day centres for people with mental disabilities and day centres for older persons. Day care services for older persons suffering from dementia are usually organised separately, primarily because of the great need for supervision and the risks to the safety of the beneficiaries. It is similar in the case of day care centres for people with mental disabilities. The activities of these services are aimed at the rehabilitation, development and maintenance of the beneficiaries' potential and their inclusion in the community. Day ser-

51 Eurostat, hlth_ehis_am7th.

52 SCP & DG EMPL, 2021.

vices for older persons, which are organised according to a club model, have a predominantly preventive role from the aspect of long-term care, and the focus is on fulfilling social needs and recreation.

Day care centres, which are an important segment of the long-term care system, are very rare in the Region. Albania has 34 centres[53], Montenegro 19, in North Macedonia there are 27 day centres across the country, including social clubs and community mental health centres.[54] In Serbia, 44 organisations[55] were licensed to provide day care services to adult beneficiaries in 2021. There are thirteen organisations in Belgrade and the rest are distributed in 30 local self-government units. There is no precise data on beneficiaries and capacities of day services in Bosnia and Herzegovina and Kosovo. Underdevelopment of the service is especially reflected on entire households, because it is a service that, in addition to supporting the beneficiary, enables family members to conduct their, usually business-relations, obligations during the day. One of the key obstacles to greater availability of this type of service is the physical distance of beneficiaries. Namely, in smaller communities, it is extremely inefficient to organise day care centres that specialize in long-term care. On the other hand, day care centres in larger towns are, as a rule, too far away to be used by citizens from the surrounding areas. Therefore, the further perspective in strengthening the availability of this service, according to experiences so far, should go in the direction of providing transportation for beneficiaries to day care centres. The services provided in the community should also be viewed from the point of view of prevention. In previous decades, in most of the region, there was a widespread practice of organising 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.

5.4 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. In Serbia and Montenegro, the law is based on a medical assessment done by the relevant medical commission. In Bosnia and Herzegovina and North Macedonia, they rely on a functional assessment through the application of the Barthel index, which is an integral part of the opinion of the applicant's family doctor.

53 International Labour Organisation, 2022.

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

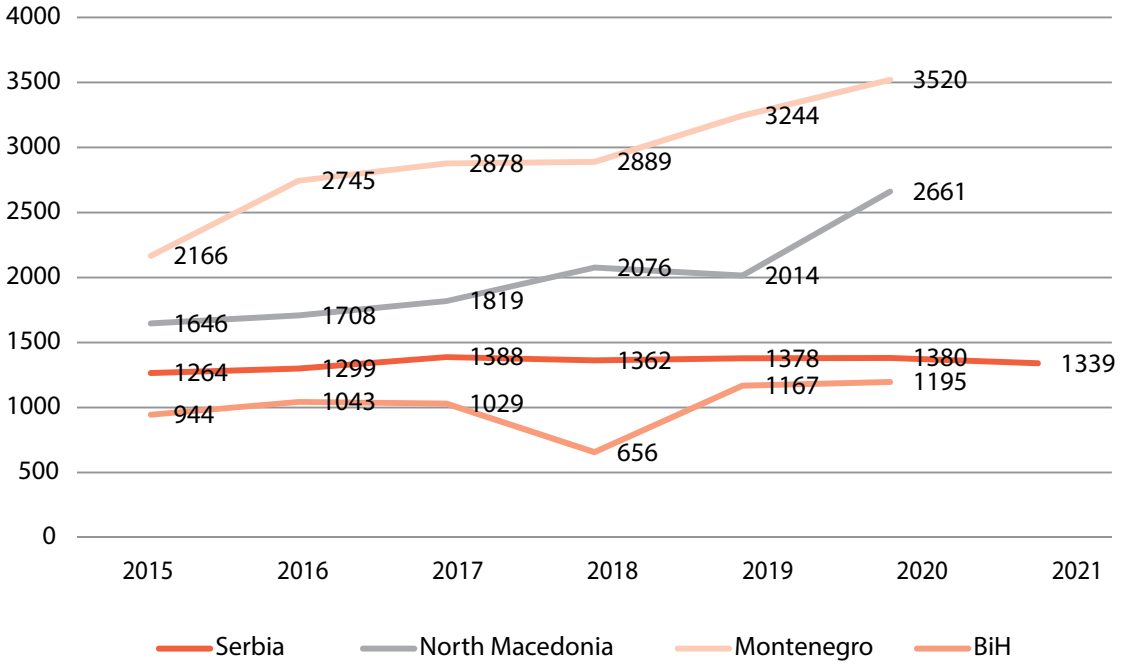
55 Republic of Serbia, Ministry of Labour, Employment, Veteran and Social Policy (s.a.)

Compensation for custodial assistance and care, as a rule, is not conditioned by the level of the beneficiary's other income and is obtained without a prior check of the financial situation. The exception is the FBiH, where in some cantons conditions that depend on the financial position of the beneficiary have been established. All systems in the Region that have this type of material benefits determine the appropriate funds from the state budget, except in Serbia. In Serbia, this right is primarily realised in the pension and disability insurance fund, and only if there are no conditions for this, funds are allocated from the budget.

Data that would provide a better insight into the coverage of benefits for custodial care and assistance are not available for all parts of the Region. According to the results of the EHIS survey, in 2019, 11% of Serbian citizens reported severe physical and sensory functional limitations, while around 1,3% of the country's residents use financial allowances intended for long-term care. Data on the share of citizens with physical and sensory functional limitations should be taken with reservation, as these are subjective views of respondents. However, the data show that the share of respondents with needs is many times higher than the share of respondents who receive financial allowances and that the above mentioned research showed that the coverage with benefits is not adequate.

Although the design of financial allowances programmes intended for long-term care in the Region is fairly uniform, judging by the number of beneficiaries, different practices have been developed. The greatest number of beneficiaries is the most conspicuous in Montenegro, even three times higher compared to Bosnia and Herzegovina. The difference between these two countries can be explained by the fact that a significant number of Bosnia and Herzegovina citizens exercise similar rights as war invalids who are not included in this overview. However, the explanation for the continuous increase in the number of beneficiaries should be sought in the practice of the authorised bodies that decide on the recognition of this right in Montenegro. The sharp increase in the number of beneficiaries in 2020 in North Macedonia can be explained by the change in the normative framework, i.e. the abandonment of the medical model and the application of functional assessment when deciding on financial allowances for custodial care. Relatively stable trends in Serbia and Bosnia and Herzegovina are expected and in line with demographic indicators.

Graph 10: Number of beneficiaries of financial allowance intended for long-term care per 100.000 citizens



Source: Calculations done by the authors for the study based on publicly available data

The adequacy of financial allowances depends on the intensity and type of care. The amounts of financial allowances are fixed in a maximum of two levels, which are sufficient to provide long-term care services of low or medium level of complexity. If it is the most complex type of care, then it should be taken into consideration that higher amounts[56] are not sufficient for the costs of residential services. This becomes especially prominent considering the increased expenses of the household due to the disability of one of its members. However, in certain circumstances of care with a lower level of complexity or lower availability of local long-term care services provided from public funds, financial allowance for custodial assistance and care may be adequate. It is difficult to give a closer assessment of adequacy in these situations, bearing in mind that the rights to local services from public funds and the rights to financial allowance are rarely synchronized in the entire region. However, the biggest doubt about the adequacy of financial allowance for custodial care stems from the broader picture of the beneficiary's living conditions. Namely, according to all indicators, the majority of people with functional difficulties have extremely low incomes and are often exposed to material deprivation. Due to the weakness of the programme of financial allowance to support low-income households, compensation for custodial assistance and care is rather used to ensure basic living conditions 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 people with functional limitations and low incomes, because only then can financial allowance for long-term care fulfil their intended function.

56 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.

Table 2: Share of financial allowances for custodial care in average salary (%)

	BiH		Montenegro	N. Macedonia	Serbia
	FBiH	RS			
Lower amount	15%–30%[57]	11%	13%	14%	15%–30%
Higher amount		22%	35%	17%	45%

Source: Calculations done by the authors for the study based on publicly available data

Financial allowances for long-term care in the EU differ considerably between its Member States. Some financial allowances are rooted in long-term programmes for people with severe disabilities[58] while others have been established since the mid-90s in response to an ageing population and increasing demand for long-term care[59] (Spasova et al., 2018:16). The right to monetary compensation usually depends on the intensity of the required care[60] although the criteria may also refer to the beneficiary's income, age or the use of other types of support. Some countries have not established special conditions for the use of financial allowance[61]. However, strict requirements are often set regarding the purpose of spending the benefit, which can only be used for the procurement of formal services or the hiring of home assistants[62]. In certain countries, the amount of compensation varies depending on whether it is used for formal or informal care, as well as the type of services used[63] and may also depend on the individual care plan[64] (Spasova et al., 2018:17). In Estonia, the benefits used to pay informal caregivers are conditioned by the long-term relationship between the beneficiary and the caregiver and the lack of availability of accredited service providers. In France, spouses are not entitled to financial allowances for long-term care. Some countries have established monetary long-term care benefits to replace the lack of formal services with financial support. According to the SILC research, an average of 46% of potentially dependent EU citizens older than 65 use long-term care financial allowances. Most of them are in Poland, Sweden and Austria, while no beneficiaries of financial allowances for long-term care over the age of 65 were recorded in six Member States.[65]

57 In FBiH the benefit amounts are regulated at the cantonal level, and in some cantons there are differences in higher and lower amounts, while in others there are none, therefore the percentage shown in the table represents the average at the FBiH level.

58 For example, Estonija, Greece, Finland, Croatia, Hungary, Romania, Slovakia.

59 For example, Austria, Germany, Belgium, Finland, Czech Republic, Luksemburg, Spain, France, Malta, The Netherlands.

60 For example, Austria, Czech Republic, Spain, Italy, Finland, France, Liechtenstein, Luxembourg, Lithuania, The Netherlands, Norway, Portugal, Slovenia.

61 For example, Austria, Italy, Lithuania, Slovenia, Slovakia.

62 For example, Spain, France, Luxembourg, The Netherlands.

63 For example, Kipar, Germany, Spain.

64 For example, Spain, France.

65 SCP & DG EMPL, 2021.

6. 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. First, long-term care beneficiaries want to remain in the privacy of their homes surrounded by their loved ones. It is understandable that the presence of a person assisting them in the house disturbs their privacy. Second, formal long-term care is costly. Even in more economically developed EU countries, more than one third of households in need of long-term care do not use professional home care services for financial reasons.[66] Also, older persons are at a lower risk of poverty when they live in multi-member households due to the care handled by other family members. Furthermore, the availability of formal long-term care services will obviously not be equal to demand for a long time, especially in smaller local communities and rural areas. Therefore, it is certainly not surprising that support for informal caregivers is getting an increasingly important place in the long-term care policies of EU countries, and such guidelines would certainly contribute to improving the effects of relevant policies in the Western Balkans. However, it should be expected that in the long term, primarily due to demographic trends, the potential of informal care will diminish. On the other hand, it should be borne in mind that state intervention cannot and probably should not completely replace family care by interfering in family relationships more than necessary.

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. The legal obligation is sanctioned and mostly limited to the closest relatives, while assisting family members and other close persons is moral in nature and subject to more complex social dynamics.

> *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).

According to research, persons with great functional difficulties mostly live in households with their spouses and children. More than half of PWDs stated that they live with their spouses and children, and this share in North Macedonia and Bosnia and Herzegovina is 70%. The exception is Montenegro, where 42% of respondents live in such households. The highest percentage of older persons in Albania and Kosovo compared to other parts of the

66 SCP & DG EMPL, 2021.

Region stated that they live together with their spouse and children (86.2% and 84.9% respectively). A somewhat lower percentage of older persons living with their spouses and children was recorded in other parts of the Region, and in Bosnia and Herzegovina, the fewest older persons by far indicated that they lived with their spouses and children (68.4%).[67]

PWDs rarely live by themselves in the household, which is not the case with older persons who have functional difficulties. Most PWDs who live alone are in Serbia, around 10%, followed by North Macedonia and Montenegro with 8% and 6% respectively. PWDs live with their parents more often, so one third of respondents stated that they live with their parents, and in Montenegro this share exceeds 50%. Compared to the PWDs, there is a larger number of people over 65 with functional disabilities, who live alone. The highest percentage in the entire Region is in Serbia and amounts to 28%. Close to one fifth of older persons respondents in North Macedonia, Montenegro and Bosnia and Herzegovina live by themselves in their household. Due to the partly preserved culture of multi-member households in Albania and Kosovo, only about two percent of respondents over the age of 65 live alone.[68]

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.[69] 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, i.e. for one fifth of respondents over 65 in North Macedonia and Bosnia and Herzegovina. However, this 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 very 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.[70]

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. In previous decades, the dominant role of the family in the care of persons with functional difficulties has been stated in the planning

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

68 Ibid.

69 Ibid.

70 Ibid.

documents. The need for support for citizens in providing care to household members is often expressed. However, such statements remain without further elaboration, direction and definition of the desired outcome.

The relevant regulations in the Region generally do not contain direct support programmes for informal caregivers. Citizens who provide care to loved ones are not classified as groups exposed to special risks. As a result, there is a lack of direct support, and their position is most often indirectly improved by improving formal support for people with functional difficulties. In Serbia, it has been established that support is also provided to families who take care of their child or adult family member with developmental disabilities through advisory-therapeutic and social-educational services. However, this type of services has remained underdeveloped. The improvement of the care provision skills is done to some extent through the work of visiting nurse services, which in some cases in the Region are organized by local health centres. The volume of home visits by nurses is far below what is required. However, it is an institutionally appropriate resource that should be further developed in this regard. All advisory and therapeutic services, and thus also psycho-social support for informal caregivers, are deeply neglected throughout the Region and rarely available to a limited range of beneficiaries with equally limited content. These services, as already mentioned, are provided only in Serbia, but these provisions of the regulations remain unimplemented. Future long-term care policies should include this type of support for informal caregivers, both in order to improve the quality of care they provide and to avoid entering into a spiral of needs going from the beneficiary to the caregiver and beyond.

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 programme 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 child care. 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 resting accommodation services. On the other hand, services such as family accommodation practically give informal care a formal character. By providing a family accommodation service, the informal caregiver becomes a service provider.

Reduced availability of long-term care services has an extremely negative impact on the position of informal caregivers. Although the services that contribute to long-term care are designed to primarily support people who cannot independently perform activities of daily living, the lack of these services is certainly reflected on the position of informal caregivers. Services, such as day care and home assistance, allow informal caregivers to devote part of their time to other activities, free from the responsibilities of providing care. Also,

the use of these services makes up for the lack of competence of informal caregivers in care segments that, due to complexity, require professional skills and knowledge that informal caregivers do not have as a rule. Also, international experiences contain examples where informal caregivers are providers of home assistance services. In this way, at the same time and under certain conditions, compensation for caregivers, appropriate training and a certain standard of quality are made possible, while care is provided to beneficiaries in a familiar and close environment. However, such programmes have not been developed in the Western Balkans.

Services that formalize the work of informal caregivers exist in the Western Balkans, but they are not organised or perceived in that way. In the first place, we mean placement with another family, which exists in the entire Region, except in Albania and Kosovo. Professionals and the general public usually see this service as an alternative to residential accommodation, however, there are not many interested potential service providers and beneficiaries. However, the importance of this service is precisely in the opportunity to enable informal caregivers, under certain conditions, to receive compensation for the care they provide, professional support, and improve their work. This especially applies to circumstances when the provision of this service is also possible in the beneficiary's apartment, as stipulated by the regulations in Bosnia and Herzegovina. Likewise, home assistance services in some EU countries can be provided by relatives and other close persons, which is a way to provide informal caregivers with compensation for their work, in accordance with the volume of care needed by the beneficiary, and to ensure an appropriate level of quality of care through the institutional service provision framework.

Improving the position of informal caregivers is one of the key trends in long-term care policies in many EU Member States[71]**.** These efforts are typically directed at: improving the social welfare of informal caregivers, introducing benefits for care and the balance between the work and private life of caregivers, strengthening competencies, psycho-social support, development of resting accommodation, etc. Several EU Member States have introduced financial allowances for informal caregivers[72]. Thus, in 2019, Slovakia established special social assistance for the care of relatives. In this way, the already existing monetary benefit for the care of a relative upon the termination of hospital treatment, which was paid in the amount of the minimum wage, was expanded. Since 2018, the Czech Republic has had a long-term care allowance that compensates for the loss of salary to people who care for their relatives after hospital treatment. In 2019, Portugal promoted the formal status of informal caregivers who continuously care for a family member in a shared household. The status of an informal caregiver, among other things, implies financial compensation depending on the amount of income. Many Member States[73] have committed to the balance between the work and private life of informal caregivers in accordance with the EU Directive[74].

71 For example, Austria, Belgium, Czech Republic, Estonia, Spain, Germany, Finland, France, Croatia, Hungary, Ireland, Lithuania, Luxembourg, Malta, The Netherlands, Poland, Portugal, Slovakia.

72 For example, Czech Republic, France, Poland, Portugal.

73 For example, Austria, Belgium, Czech Republic, Estoniia, Spain, Croatia, Portugal.

74 The European Parliament and The Council of The European Union, 2019.

Since 2019, Belgium has enabled extended leave for employees to provide informal care under special conditions. In 2019, Austria legally established the right to leave for care, without the prior consent of the employer, which applies to companies with more than five employees. In 2019, France introduced an incentive for the use of leave from work by informal caregivers in the form of monetary compensation, because employees rarely decided to use this right while employed. Also, informal caregivers are protected in France from termination of employment contracts. In 2016, Finland increased leave to at least two or three working days per month for informal caregivers who conclude an informal care contract with the municipality. The development of resting services and the improvement of the competencies of informal caregivers were also part of the reform programmes[75]. With the Law on Social Services, Bulgaria introduced support and training services for family members who provide informal care at home, and informal caregivers were given the right to resting services. In 2017, Ireland implemented a training and support programme for family caregivers funded by unused funds in inactive accounts with credit institutions and unclaimed life insurance policies. In Finland, informal caregivers are supported by special health care programmes, and since 2018 they are entitled to training provided by municipalities.

75 For example, Bulgaria, Germany, Estonia, Finland, France, Ireland, Lithuania, Luxembourg, Poland, Portugal.

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