

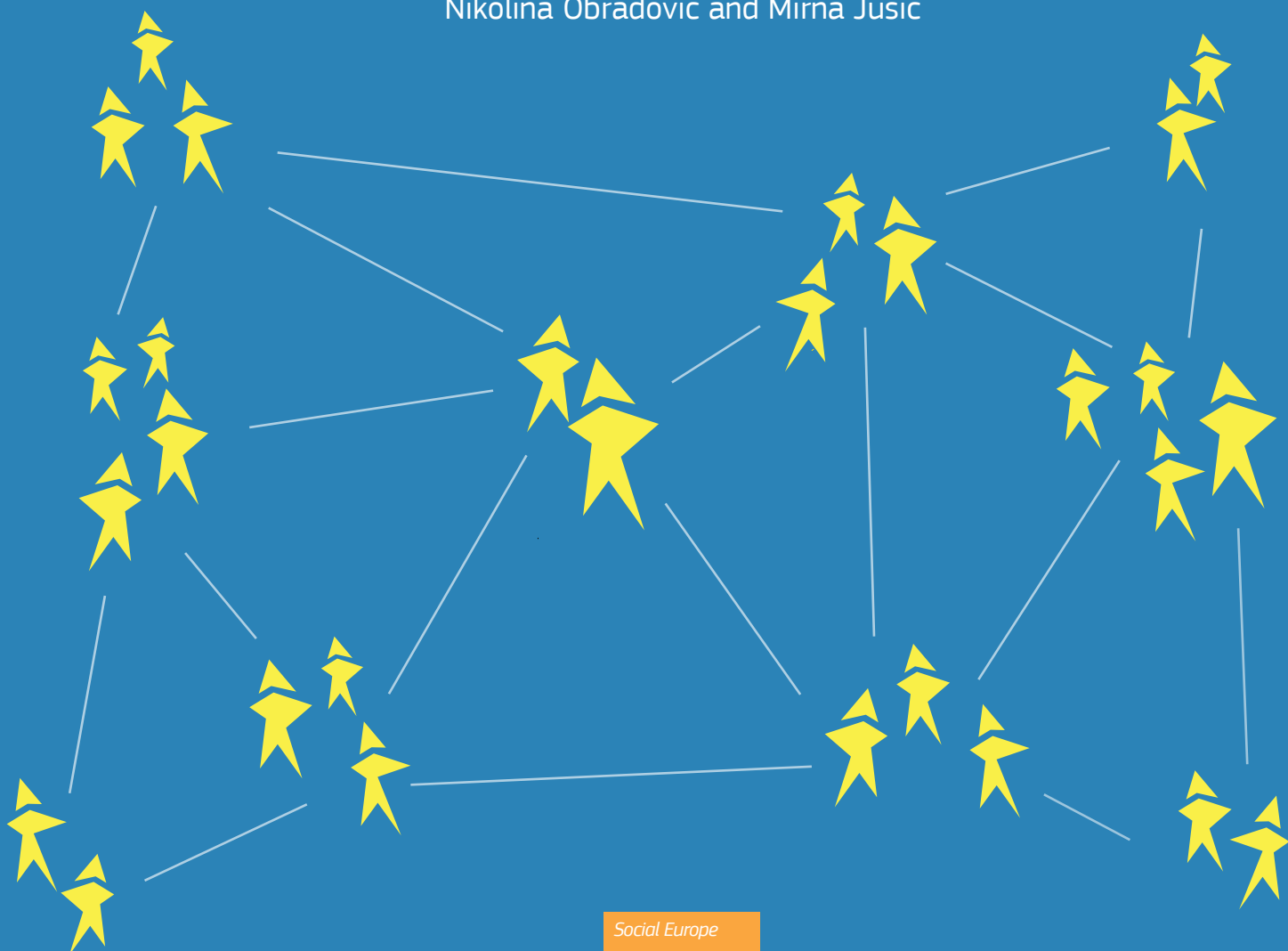


EUROPEAN SOCIAL POLICY NETWORK (ESPN)

Long-term care for older people

Bosnia and Herzegovina

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EUROPEAN COMMISSION

Directorate-General for Employment, Social Affairs and Inclusion

Directorate C — Social Affairs

Unit C.2 — Modernisation of social protection systems

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European Social Policy Network (ESPN)

**ESPN Thematic Report on
long-term care for
older people**

Bosnia and Herzegovina

2021

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The European Social Policy Network (ESPN) was established in July 2014 on the initiative of the European Commission to provide high-quality and timely independent information, advice, analysis and expertise on social policy issues in the European Union and neighbouring countries.

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Manuscript completed in September 2020.

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Quoting this report: Obradovic, Nikolina and Jusic, Mirna (2021). ESPN Thematic Report on Long-term care for older people – Bosnia and Herzegovina, European Social Policy Network (ESPN), Brussels: European Commission.

CONTENTS

HIGHLIGHTS.....	4
1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM.....	5
1.1 Demographic trends	5
1.2 Governance and financial arrangements	5
1.3 Social protection provisions	6
1.4 Supply of services	7
2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY	9
2.1 Access and affordability.....	9
2.2 Quality	10
2.3 Employment (workforce and informal carers).....	11
2.4 Financial sustainability	12
2.5 Country-specific challenges regarding LTC for other age groups in need of care	13
3 REFORM OBJECTIVE AND TRENDS	14
4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES	15
REFERENCES	16
STATISTICAL ANNEX 1.....	20
STATISTICAL ANNEX 2.....	22

Highlights

- Despite negative population growth and an ageing population, Bosnia and Herzegovina (BiH) does not have in place a system of long-term care (LTC) that would universally cater to the needs of those with a degree of long-term dependency. Instead, some elements of LTC are present within systems of social protection and health protection.
- LTC schemes and services constituted merely 0.55% of the country's GDP in 2017¹, of which 82% pertained to the system of social protection and the remaining part to healthcare. Available statistical data suggest that services are provided to only a limited number of beneficiaries, raising concerns about the accessibility, equality and equity of such provision.
- The country is in the early phase of developing quality standards for services in the realm of LTC. There is no organised system of cooperation between the health system and the system of social protection in the provision of services.
- As a result of limited provision of services, most of the brunt of LTC is borne by families, especially the women in the household. It is likely that the informal market for care services is considerable, but there has not been any research on this.
- In the future, demand for LTC is likely to increase, not only because of population ageing, but also due to a decline in the size of the family and emigration trends, which are likely to affect the availability of both formal and informal carers. The responsible levels of government must urgently begin to address the gaps in LTC provision.

¹ Agency for Statistics of BiH data received 14 April 2020 (on file with authors).

1 Description of main features of the long-term care system

1.1 Demographic trends

Bosnia and Herzegovina (BiH) has a negative population growth rate, caused primarily by decreasing birth rates; in recent years the latter have additionally been aggravated by the emigration of the population of fertile age. At the same time, life expectancy is increasing and the average age at death is on the increase. The latest data for 2017 (Agency for Statistics of BiH, 2018, p.54) show that the average age at death for women was 76.5 and 73.9 for men. As shown in Annex 1, the most recent data on life expectancy are available only for the age group 65-69 for the two entities of BiH – the Federation of BiH (FBiH) and Republika Srpska (RS). We can observe that there are no significant differences between the entities, but women in general have a higher life expectancy than men – 15.59 vs 17.84 in FBiH, and 15.44 vs 17.85 in RS. Estimates of healthy life expectancy at age 65 are not available.

According to the last census data for 2013 (Agency for Statistics of Bosnia and Herzegovina, 2020), the average share of the population aged 65 and older in the country was 14.2%, albeit with large regional differences. For instance, the largest share of the population aged 65+ was found in RS (17.1%) and some cantons in FBiH, such as Canton 10 (17.7%). On the other hand, in FBiH, the average share of the population aged 65+ was 12.9%, with the smallest share found in the Una-Sana Canton (10.7%) (FBiH Ministry of Labour and Social Policy, 2018, p.6). In the five-year period since the last census, the share of people aged 65 and older has increased by 1.76 percentage points, up to 15.96% in 2018, which indicates a rapid ageing process. Furthermore, it is relevant to note that households are becoming smaller, with the share of single-person households being on increase. In 2013, the share of single-person households was 19% (Agency for Statistics of BiH, 2018, p. 23). This trend is particularly pronounced in rural areas, as young people tend to emigrate to urban centres or abroad.

If such trends continue, we can expect a further population decline, with increased shares of the population aged 65 and older. The United Nations estimates that, within a ten-year period, the BiH population will decrease to 3.1 million, with the share of the population aged 65+ reaching 24.1%; by 2050, it will make up more than 30%, and the total population would shrink to 2.6 million (United Nations, Department of Economic and Social Affairs, Population Division, 2019).

1.2 Governance and financial arrangements

Constitutional competencies for health and social protection in BiH are within the responsibility of the two entities. In FBiH, constitutional competencies for social protection and health protection are shared between the entity and its ten cantons. The FBiH Law on the Principles of Social Protection (Official Gazette FBiH 36/99, 54/04, 39/06, 14/09, 45/16 and 40/18) serves as a framework and general law on social protection², and provides for a number of rights and benefits. Its beneficiaries include people with disabilities and older people without family care, *inter alia*. The framework law in FBiH envisages benefits for people with disabilities within two categories (so called non-war people with disabilities and civilian victims of war) who are entitled to an individual disability allowance, a care allowance and an allowance for orthopaedic aid. In addition, war veteran legislation guarantees similar entitlements to war veterans with disabilities.

The provision and financing of services, such as home care and assistance, placement in institutional care, foster care, and other services, are devolved to local government level

² The so-called social protection legislation in both entities has a rather narrow meaning, as it denotes benefits financed from the budget and social services targeted towards people and families in social need.

(i.e. cantons and municipalities). Each canton is responsible for enacting its social protection legislation and, depending on its needs and financial possibilities, may guarantee additional rights and benefits.

Although RS is centralised, the RS Law on Social Protection (Official Gazette of the Republika Srpska 37/12) stipulates shared competences for social protection between the entity and municipalities, and thus foresees shared responsibilities for the financing of benefits and the provision of services.

In both entities, lower levels of government (i.e. cantons and municipalities) may provide and finance extended rights beyond those stipulated by the general social protection legislation. The administration of all benefits and services for people in social need are administered by municipal centres for social work (CSWs) or social services.

The healthcare system in the country is established upon Bismarckian principles, with compulsory health insurance financed mainly from payroll contributions (Obradović and Jusić, 2019). The health system in FBiH is decentralised; each canton has its own independent system made up of a health fund and health service providers (such as health centres, specialised medical care, and hospitals). Each canton has its own ministry of health, while the Ministry of Health of FBiH is responsible for coordination and framework legislation. The health system in RS is centralised, falling within the competency of the entity. Although LTC expenditure is reported within the national health accounts, neither entity has classified LTC services as a part of healthcare standards and norms. This means that LTC services are not provided per se within the health sectors. However, some health services could be considered as a type of LTC, such as tertiary care provided to patients for the duration of treatment, palliative care provided in two specialised hospitals in RS (in Gradiška and Nevesinje), and patronage care organised by some health centres.

1.3 Social protection provisions

The only benefit resembling an LTC benefit is the allowance provided to people with disabilities in need of care and assistance by another person (hereafter: care allowance). However, given the country's decentralised organisation and devolved competencies for social protection, the amount of the care allowance differs depending not only on the region, but also on beneficiaries' status. In both entities, people with disabilities are divided into three status groups³, depending on the cause and type of their disability. These include war veterans with a disability⁴, civilian victims of war⁵, and people with a disability under social protection legislation, who cannot be assigned to the previous two status groups. For each status category, financial benefits⁶ are granted for different degrees of disability: for the war veterans, it ranges from 20% to 100%; for civilian victims of war, from 60% to 100%, and for people covered under social protection legislation, it ranges from 90% to 100% in FBiH and from 70% to 100% in RS).

For all categories of beneficiary in FBiH, the assessment of disability is conducted by a single institution – the FBiH Institute for the Medical Evaluation of Health Status. In RS, the assessment is conducted under the oversight of the institution responsible for administering the benefit; that is, the centre for social work or responsible ministry. The assessment of disability for each group is conducted under different rules by applying a medical model. The exception is the assessment of disability as part of RS social protection legislation, which is conducted by assessing the beneficiary's functional ability to perform daily tasks and personal hygiene based on the so-called Barthel test (RS Official Gazette

³ The fourth group are people whose disability was caused by an injury at work or by occupational illness. Their rights are recognised under the general law on pensions and disability insurance.

⁴ Members of one of the recognised armies who were in duty during the 1992-1995 war, when their injuries or a disability happened.

⁵ Civilians (not members of the military) whose disability was caused by the war or remnants of the war.

⁶ Benefits might include a disability benefit, the care allowance, and assistance for an orthopaedic aid.

116/12, 111/13 and 9/17). Although the care assistance is primarily intended for people with disabilities, this provides the possibility for people without a disability who are older and frail to receive the benefit. Disability benefits envisaged by the entity legislation are not means-tested and do not depend on a person's employment status or age. However, these benefits are means-tested when included under social protection legislation in cantons. Furthermore, under the social protection legislation, the use of a care allowance precludes the use of the right to be placed in an institution of social protection.

With regards to the care allowance, the benefit can be granted for partial or complete dependence on the assistance of another person for daily living activities. Under the social protection legislation, the amount of the benefit in FBiH is €140.70 and €70.36, while in RS it was €87.90 and €44 during 2019. The care allowance for war veterans with a disability in FBiH ranges between €440 and €220 depending on the degree of disability, while civilian victims of war receive 70% of the amount of the war veteran's benefit, which is €305.10 for category I, €213.57 for category II and €152.55 for category III. The amount of the care allowance for war veterans and civilian victims of war in RS is arranged in a similar way to that in FBiH. Cantons in FBiH may grant additional rights for these categories.

The country does not have a register of people with disabilities. The available statistical data on the number of care allowance beneficiaries for the country are incomplete and inconsistent. For instance, the RS Ministry of Health and Social Welfare (2019b, p. 8) states that the total number of care allowance beneficiaries in RS for the year 2018 was 26,394 (for both I and II category), while, according to the Agency for Statistics of BiH (2019b), the total number of care allowance beneficiaries (minors and adults) in the same year for the entire country was 25,142. Furthermore, the available data on beneficiaries are not disaggregated by age and gender, nor the status of the beneficiary, which would be relevant in the case of BiH. It is important to note that 2015 household budget survey data suggest the presence of a gender gap in terms of the disability status, as 11.1% of men and only 5.2% of women were describing as having a 'decision on disability' from a commission or institute⁷.

In both entities, the provision of services is devolved to local communities. However, RS law defines beneficiaries and eligibility criteria. These include frail people, those who are gravely ill, and those who cannot perform activities of daily living. Care and assistance services for these people should be financed from the municipal budget, subject to the condition that they do not have relatives who could take care of them, or they or their relatives do not have sufficient means (the beneficiary's total income must not exceed 50% of the average net salary in the previous year). In FBiH, eligibility criteria are defined by cantons or municipalities, and are usually means-tested on the same principles as in RS. Home care and assistance may include household chores, help with personal hygiene, supplying food and feeding, and other activities of daily living. RS law envisages that these activities can be provided by institutions of social protection, citizens' associations, religious communities, and other legal subjects that fulfil eligibility criteria defined by the responsible ministry.

1.4 Supply of services

Despite legal provisions and the growing need for them, home-based care services are available only in a few, more developed municipalities. Sarajevo and Banja Luka are the only two cities with public gerontology centres that provide home care services, which include basic healthcare as well as personal and household assistance, depending on beneficiaries' needs. In some municipalities, these services are provided in cooperation with the local Red Cross. However, the available statistics suggest that home care and assistance is not widely available. As presented in Table A2.1 in the Annex 2, in recent years home care assistance has been provided to around 200 people in RS and between

⁷ Agency for Statistics of BiH data received 14 April 2020 (on file with authors).

100 and 200 people in FBiH. These are negligible numbers considering population ageing and the sheer size of the older population in some regions, as well as the number of people with disabilities.

Placement in an institution of social protection, such as a home for people with disabilities or a retirement home, is another option provided through the system of social protection in the country. Institutional elderly care was delivered by 49 institutions in FBiH in total in 2018 (Institute of Statistics of FBiH, 2019, p. 72). There are some 30 private healthcare institutions registered for taking care of the elderly in Brčko District (Otisak, 25.10.2019). In RS, four institutions for the elderly established by the entity or local governments and 32 private or non-profit residential institutions for the elderly operated in 2019 (RS Ministry of Health and Social Welfare, 2020). For many families, placement in an institution becomes the last resort once they can no longer manage the care of a family member on their own. As home care services are mostly unavailable, placement in an institution is a solution for many older people living alone who cannot perform activities of daily living. In cases where a beneficiary's income (including the income of their relatives) is not sufficient, their stay in an institution can be subsidised by the municipality. According to the Agency for Statistics of BiH (2019b, p. 64) the number of adults in institutions has increased substantially in recent years (by 65% since 2013) to 6,284 in 2018. In the same period, the share of people aged 80 and older more than doubled (in 2018, they made up 44% of all residents). Such an increase can be attributed to a rise in the capacity of the private sector⁸.

Legislation on social protection envisages the possibility of placing both minor and adult beneficiaries in foster care, where they can be provided with care and assistance. During 2018, 39 people aged 65 and older were using foster care in RS (RS Ministry of Health and Social Welfare, 2019b, p.14)

⁸ Most privately owned institutions are registered as not-for-profit.

2 Assessment of the long-term care challenges in the country

2.1 Access and affordability

Different eligibility and entitlement criteria for a care allowance between entities and between cantons in FBiH have implications for both access to, and the affordability of, care services. Beyond territorial discrepancies, there are also significant differences between beneficiary categories: two people may be in need of the same level of care, but the amount of the care allowance they receive depends on the beneficiary category they fall into. As noted earlier, war veterans and other war-related categories of beneficiaries are entitled to a higher allowance than other people in need of care. Moreover, for war-related categories, requirements are lower regarding the level of disability one has to have in order to realise the right to an allowance.

The affordability of in-home LTC services on the basis of out-of-pocket spending for different levels of severity of needs is difficult to assess due to a lack of available data on the cost of in-home services. What is certain is that a care allowance for non-war related categories of beneficiaries is considered to be very low, and is thus not sufficient to meet a person's need for care (Malkić and Numanović, 2016, p. 5).

Numerous challenges also exist with respect to access to the types of care services available in the country. As mentioned earlier, social protection legislation at entity and cantonal level provides for a variety of LTC-related services, including home care and assistance, day care, institutional care and foster care. Beyond legislation, not all localities have been able to establish such services, usually due to a lack of funds. Generally speaking, community-based services remain underdeveloped in the country, there are wide territorial disparities in terms of their provision, and their delivery often depends on non-governmental organisations that provide them on a project basis, frequently with the support of international donors rather than governments.

The most commonly provided service in the realm of LTC is institutional care, which for older people is provided in specialised residential institutions for the elderly and the frail⁹. According to the RS strategy for improving the situation of older people, in 2018 the vast majority of the capacity in both the private and public sector was filled (RS Ministry of Health and Social Welfare, 2019a, p. 18; p. 22). As mentioned earlier, available data suggest that the demand for residential care among the elderly has been rising.

The affordability of residential care services is low considering the average pensions and average income in the country, as such services are generally paid out-of-pocket. The prices depend on a person's degree of dependence, and range from €333 to €650. Prices in privately owned institutions are, on average, 50% higher than in publicly owned ones. Such prices are steep considering that the average pension in FBiH was €215.10 and €201.10 in RS in February 2020 (RS Pension Insurance Fund, 2020). CSWs will cover the cost of an older person's placement only after determining that a person has no means or income, and that there are no family members who are legally responsible to care for them. As a result, in 2018 only 8.9% of adults placed in institutions had their stay covered in full from public budgets, 18.7% received partial coverage of their costs, and 72.3% had to cover their stay in full (Agency for Statistics of BiH, 2019b, p. 64). Albeit waiting lists for both public and private facilities are reported to be long, waiting lists of public facilities tend to be longer because of their lower prices.

As mentioned earlier, people receiving a care allowance cannot have their stay in an institution covered from public budgets. In some parts of the country, they have to choose between an allowance or government-financed in-home care and assistance services.

⁹ In some circumstances, it may also be provided by health institutions and institutions for people with disabilities, depending on the type of disability.

Given that people in need of LTC frequently live in poverty and use their care allowance as a form of budget support, many opt for an allowance (Malkić and Numanović, 2016, p. 6).

Most rural areas do not have a health centre in their vicinity, nor available public transport (Obradović, Jusić and Mihailovic, forthcoming). While those living in urban areas have access to primary healthcare, and may also have access to specialised institutions catering to the elderly that organise home visits, older people in need of care living in rural areas rarely have access to such services (see, for instance, RS Ministry of Health and Social Welfare, 2019a, p. 14). Community nursing, usually delivered by non-governmental service providers, is available in only a few vicinities; some municipalities may organise patronage services to reach out to people living in remote areas.

Another problem in terms of access and affordability is that health insurance coverage in BiH is not universal. Older people who are not covered by pension insurance or social benefits are usually without health insurance. Although social protection legislation in both entities envisages health insurance coverage for people aged 65+, it is not unconditional (Institution of the Human Rights Ombudsman of Bosnia and Herzegovina, 2019, p.51). The World Health Organization (2020) estimates out-of-pocket expenditure¹⁰ to be as much as 29.1% of all health expenditure in 2017, suggesting that health services may not be affordable to all.

The lack of access to affordable LTC services strongly affects older people living in poverty. The Agency for Statistics of BiH, based on the 2015 household budget survey consumption data, points out that the risk of poverty is highly correlated with old age (Agency for Statistics of BiH, 2018, p.64). The situation of older people living in poverty, without relatives and in need of LTC, is compounded further if they reside in rural areas – an institutionalised, proactive approach to recording the needs of people seeking LTC and providing them with care is generally absent in such areas, often resulting in people’s social exclusion (Malkić and Numanović, 2016, p. 7).

2.2 Quality

The legal framework in BiH is still in the early phases of development with respect to ensuring quality service standards in different realms of care. This is especially the case in the more decentralised FBiH. The quality of social services is governed by various social protection laws at entity and cantonal level, as well as bylaws. FBiH has adopted a rulebook on the standards for work and service delivery in social welfare institutions in FBiH (FBiH Official Gazette 15/13, 44/16). Similarly, RS has adopted a rulebook on the conditions for establishing a social welfare institution and performing social welfare services (RS Official Gazette 90/17). Such rules stipulate the minimum standards and criteria a service provider has to meet in order to be licensed as a social welfare institution or, in the case of RS, to be able to deliver social services. Licensing approval mainly depends on meeting formal requirements, such as adequate premises, necessary equipment, and the number and training of staff, in line with the service provided. On the basis of such bylaws, FBiH, cantonal and entity (in RS) inspectorates oversee providers’ work; in some instances, residential homes for the elderly have been closed for not meeting required standards.

Social welfare institutions in both entities are subject to professional oversight. RS has adopted a rulebook on professional oversight (RS Official Gazette 15/15), which mandates oversight over the delivery of services in the social welfare realm. In FBiH, such oversight is exercised by the competent entity ministry for institutions established by FBiH; and by the competent cantonal ministry for institutions established by the canton (or municipality). However, occasional media reports about abuse and neglect of residents placed in institutional care (Radio Free Europe, 2019; Oslobodjenje, 2018) indicate the lack of professional oversight in these institutions.

¹⁰ Refers to direct payments by individuals to health service providers as a percentage of current health expenditure.

In terms of home-based care, RS has also adopted the rulebook on realising the right to in-home assistance and care (RS Official Gazette 2/14), which – beyond eligibility criteria – also details what such services entail, who is allowed to provide them, and how they are to be provided. For instance, in-home assistance and care services are to be performed in line with an individual plan; tasks need to be clearly defined; services cannot be provided for less than five hours a week or more than 20 hours a week, and have to be delivered at least three times a week; and services have to be delivered by qualified staff and should be delivered by the same employee. Regular monthly reporting on the delivery of services by the service provider to the competent CSW is mandated by this document. RS has also adopted a rulebook stipulating standards for the provision of day care services, which similarly mandates the conditions for provision of such care.

Specific decisions setting standards for the provision of these types of services have not been adopted by governments in FBiH; but individual services, such as in-home care and assistance by institutions of social welfare, are addressed by the general rulebook on the standards for work and service delivery in social welfare institutions in FBiH, which specifies conditions mainly in relation to the necessary facilities, equipment, and the number and profile of staff per hours of service delivery. Any closer conditions are thus the subject of individual service providers' rules.

In FBiH, measures of health protection for people who are in need of LTC in social welfare institutions (including homes for the elderly) – such as facilities, equipment, and staff – was supposed to be regulated, under the FBiH Law on Health Protection (Official Gazette 46/10 and 75/13, Article 94), by decisions of cantonal ministries of health. However, such decisions have not been adopted (e.g. see: Gerontološki Centar Sarajevo, 2015, p. 10), which has implications for the capacity of social welfare institutions to deliver healthcare services.

There are no specific decisions that regulate the realm of informal care in BiH; this area of care has, thus far, been completely outside the purview of policymakers.

2.3 Employment (workforce and informal carers)

Given that BiH is an ageing society (see Section 1 above), it will inevitably face the challenge of ensuring an adequately sized and trained LTC workforce in the long term. Unfortunately, comprehensive indicators on the number of formal and informal LTC workers in terms of their number and characteristics are not available. The only available data are on the number of employees in institutions for the elderly for the two entities (please see Table A2.2 in Annex 2). An increase in the number of healthcare and other professional workers can be attributed to an increase in the number of residential institutions that are being opened by the private sector.

Given that there is no comprehensive information on the LTC workforce, it is difficult to assess whether or not the sector is facing workforce shortages. Some reports do suggest that this is the case, at least when it comes to the number of trained medical professionals who would be able to treat elderly patients with certain medical conditions. According to both entities' strategic documents on improving the position of older people, residential institutions for the elderly report an increase in the placement of older people with various medical conditions, including Alzheimer's. At the same time, there is a lack of physical capacity and trained staff to treat such patients (FBiH Ministry of Labour and Social Policy, 2018, p. 11; RS Ministry of Health and Social Welfare, 2019a, p. 16).

In BiH, care workers working in the formal sector have to have a certain educational background to perform such services. The qualifications needed depend on the profile of the carer; medical nurses, for instance, usually have to have completed at least secondary medical school and pass the expert exam in their field; carers – who look after the everyday needs of the person in need of LTC, including their hygiene, and who may provide support to medical nurses – usually have to have completed at least elementary school. There have been initiatives to provide education in the realm of care for elderly people, specifically by the non-governmental sector. Training courses in this realm have been provided by NGOs

such as the Red Cross or local citizens' associations (see, for instance, Red Cross of Tuzla Canton, 2020; Citizens' Association Centre Fenix, 2018; Socio-educational Centre, 2020), some of them financed by students, and others fully sponsored by international donors.

There is no support in place for people providing informal care, neither in the form of financial compensation for the services rendered, nor in the form of respite care, training or counselling. Moreover, informal carers are not protected by the social security system while performing care functions (Malkić and Numanović, 2016).

As BiH has been facing significant emigration by its younger population to the EU, and especially medical and care workers who generally have low wages in this sector in BiH, more significant workforce shortages may be expected.

2.4 Financial sustainability

Judging by available data, BiH currently spends very little on the LTC function, a mere 0.55% of the country's GDP. Spending on LTC in the health realm has been stable at 0.10% of GDP. In terms of purchasing power standards (PPS), it was 9.33 PPS per inhabitant in 2017, which was among the lowest in Europe (Eurostat, 2020).

Spending on LTC as part of social protection was 0.55% of GDP in 2015 and 2017¹¹. Such statistics do not take into account the cost associated with the provision of informal care, nor out-of-pocket payments by beneficiaries. The 2017 spending data indicate that 15.7% of total LTC spending is on institutional care, while 66.3% is on care allowances (for more, see Annex 1). The out-of-pocket spending on institutional care is much higher than government spending, but there is no available information on that.

Available disaggregated data on spending on care allowances and LTC-related services over the years, available for RS, show that there was a rise of 48% in expenditure on care allowances (for all age groups) between 2014 and 2018 (please see Table A2.3); these allowances are co-financed by the entity and local government (50% each), and entailed some €17.6 million of spending in 2018. On the other hand, there has been a mere 2% rise in expenditure on in-house assistance (all age groups) between 2014 and 2018, and local government, which is in charge of financing such services, spent only circa €156,226 in 2018. In the realm of day care services (all age groups), there was a rise in expenditure of 16% between 2014 and 2018, but spending on such services by local government also remained at a very low level, amounting to circa €190,827 in 2018¹².

There are no projections for BiH on future levels of public spending on LTC. However, one may foresee a rise in expenditure on formal care and a further development of the LTC system, given an ageing population. This is already suggested by an increase in the number of elderly people being placed into institutions on an annual level. Given the lack of data on informal care, it is unclear whether a significant shift between informal and formal care may be expected; nevertheless, given a rise in single-person households among the elderly in the past three decades, and a strong trend towards emigration by the country's younger population, a decline in the prevalence of informal care provided by family members may be anticipated, suggesting that such services could become less widespread.

¹¹ Data provided by Agency for Statistics of BiH on 14 April 2020 (on file with authors).

¹² Day care facilities may not only cater to people in need of LTC. Data on the financing of placements were only available for all social welfare institutions, not LTC-specific institutions, and were thus not taken into account.

2.5 Country-specific challenges regarding LTC for other age groups in need of care

Other age groups in need of LTC in BiH face many of the same challenges as older people. Inadequate financial support and an absence of care services hamper access to care by children and adults with disabilities. Despite being a signatory of the UN Convention on the Rights of Persons with Disabilities, BiH is still in the early stages of implementing deinstitutionalisation. The UN Committee for the Rights of Persons with Disabilities (2017) has pointed out that resources are still being invested in renovating or extending institutions, while initiatives for community-based services enabling independent living are insufficiently supported. There are also concerns over the different legal entitlements for people with disabilities, and the different assessment of the same disability based on beneficiaries' status.

In November 2019, a FBiH Member of Parliament unveiled photographs of residents of the Pazarić Institution for the Care of Intellectually Disabled Children and Youth, a FBiH public institution, being tied to beds and radiators (Radio Free Europe, 2019); this led to a protest in Sarajevo, and the condemnation of such abuse by the Council of Europe's Commissioner for Human Rights. However, beyond the replacement of the management of that particular institution by the FBiH government, no concrete measures towards the improvement of services or deinstitutionalisation have been implemented.

Parents in both entities face a lack of community-based and home-care services, as well as a general lack of integrated social and health services for children with disabilities. They also find themselves in a difficult position in terms of being able to work and care for their children. Following an initiative by the Sarajevo-based association of families of children and people with disabilities (Give us a Chance), the House of Representatives of the FBiH Parliament adopted a draft law on changes to the FBiH Law on the Principles of Social Protection (please see Box in Section 3), whereby the status of a parent taking care of a child with disabilities would be recognised. In RS, 2019 changes to the Law on Child Protection introduced the status of a parent-carer.

The labour legislation of both entities foresees that the parent of a child with developmental difficulties may work part time. In RS, the employee's lost salary is compensated for from the RS Fund for Child Protection. This is unregulated in FBiH, where an employee will receive the salary that corresponds to the actual hours worked.

3 Reform objective and trends

Pertaining to the elderly, BiH has a number of strategic documents that address the realm of LTC to some extent. In line with the Madrid international action plan on ageing and the European Social Charter, both entities have developed strategies on improving the position of older people. The FBiH strategy is still in draft form (FBiH Ministry of Labour and Social Policy, 2018), while RS adopted such a strategy for the 2019-2028 period at the end of 2019. These strategic documents, although not specific to LTC, do foresee some reforms in the LTC realm, such as enhancing alternative forms of care to institutional care (community- and home-based); adopting a common legal framework mandating social service standards in FBiH; and generally improving the position and the community participation of elderly people.

Other relevant strategic documents include the strategy on deinstitutionalisation and transformation of social protection institutions in FBiH (2014-2020), the FBiH strategy for the advancement of rights and status of people with disabilities (2016-2021) and the RS strategy for improving the social position of people with disabilities (2017-2026). All of these strategic documents, as part of deinstitutionalisation efforts, foresee the development of community-based services. Significant steps in developing such services have not yet been taken.

The only ongoing reform in FBiH pertains to the issue of parent-carers (See Box below). RS introduced the status of a parent-carer in December 2019, introducing benefits for an unemployed parent taking care of a child with a 100% disability in the monthly amount of circa €57 a month.

Planned reforms and ongoing legislative process and debates

Currently going through parliamentary procedure are draft amendments to the FBiH Law on the Principles of Social Protection. The amendments provide for recognition of the status and rights of parents caring for children with disabilities, stipulating that such carers would have the right to a monthly benefit and to social insurance. However, the initiative did not have initial approval from the responsible ministry (please see Jusić, 2019).

4 Main opportunities for addressing LTC challenges

Under the systems of social protection in both entities, the brunt of LTC is borne primarily by families. Families have a legal obligation to care and provide for their dependent members, be it someone with a disability or an older and frail family member. Government-financed care allowances are insufficient and discriminatory, while services are scarcely provided and are underfunded. In such circumstances, the demand for institutional care is increasing, and it is being met by the private sector, with new retirement homes being opened by non-governmental organisations and private capital. This is contrary to the government's commitments on deinstitutionalisation.

The absence of a publicly provided system of LTC raises questions of equity and equality. It has serious consequences for gender equality in the country, as informal or family carers are usually women. Care work creates impediments to their participation in the labour market and their formal employment. At the same time, they are often exposed to a heavy workload and need support in terms of expert advice, respite care and other services. As formal services are unavailable, the only option for those who wish to participate in the labour market is to employ a carer or to resort to placement in institutional care. The illegal market for care providers in the country is probably considerable. The majority of informal carers are women and most of them are unregistered workers, without social insurance and any support services. Measures that would contribute to legalising employment in this sector would increase the employment rates of women and secure their social rights. In addition, the legalisation of care work would foster an improvement in the standards of care work, which may be enhanced through certification, training, and expert support services. Where available, local government should use the potential of the NGO sector to organise the care or support services in the area of their competence.

The country should invest in improving statistics, harmonising standards for the entire country and making data available by age and sex. The existing surveys conducted in the country (the labour force survey and household budget survey) should be adjusted to capture information on dependency and the demand for, and supply of, LTC.

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Statistical annex 1

Table A1.1 Demographics

		2013	2018	2030*	2050*
Population (in millions)		3.5	3.5	3.1	2.6
Old-age ratio		20.20	22.91	n.a.	n.a.
Population 65+ (in millions)	<i>Total</i>	0.501996	0.558489	0.753	0.816
	<i>Women</i>	0.209144	n.a.	n.a.	n.a.
	<i>Men</i>	0.292852	n.a.	n.a.	n.a.
Share of 65+ in population (%)		14.20	15.96	24.1	30.4
Share of 75+ in population (%)		5.9	6.6	n/a	n/a
Life expectancy for the age group 65-69 (in years)	<i>Total</i>	(FBiH 15.94)	(FBiH 16.82) (RS 16.74)	17.6	19.7
	<i>Women</i>	(FBiH 17.01)	(FBiH 17.84) (RS 17.85)	n.a.	n.a.
	<i>Men</i>	(FBiH 14.63)	(FBiH 15.59) (RS 15.44)	n.a.	n.a.

* United Nations, Department of Economic and Social Affairs, Population Division (2019)

n.a.: data not available.

Source: Agency for Statistics of Bosnia and Herzegovina, the FBiH Institute for Statistics, and the RS Institute for Statistics.

Table A1.2 People in need of LTC

		2015	Most recent	2030	2050
Number of potential dependants (in thousands)		n.a.	n.a.	n.a.	n.a.
Number of potential dependants 65+ (%), HBS 2015	<i>Average</i>	47.9	n.a.	n.a.	n.a.
	<i>Women</i>	52.9	n.a.	n.a.	n.a.
	<i>Men</i>	40.7	n.a.	n.a.	n.a.
Share of potential dependants in total population (%)		n.a.	n.a.	n.a.	n.a.
Share of population 65+ in need of LTC, defined as having at least one severe difficulty in personal care and/or household activities (%)		n.a.	n.a.	n.a.	n.a.

n.a.: data not available.

Source: 2015 Household Budget Survey

Table A1.3 Access to LTC

	2014	2018	2030	2050
Share of population 65+ receiving care in institutions for adults (%)	0.66	1.03	n.a.	n.a.

* ADL: activities of daily living; IADL: instrumental activities of daily living

Source on number of residents: Agency for Statistics of BiH 2019, p. 64. 2013 Census data available at: popis.gov.ba

Table A1.4 LTC expenditure

	2015	2017	2030	2050
Public spending on LTC as % of GDP (ESSPROS)	0.55	0.55	n.a.	n.a.
Public spending on institutional care as % of total LTC public spending (ESSPROS)	14.40	15.7	n.a.	n.a.
Public spending on home care as % of total LTC public spending	n.a.	n.a.	n.a.	n.a.
Public spending on cash benefits as % of total LTC public spending (ESSPROS)	68.15	66.3	n.a.	n.a.
Government and compulsory contributory financing schemes as % of GDP, LTC Health (NHA)	0.10	0.10	n.a.	n.a.
Government and compulsory contributory financing schemes as % of GDP, LTC Social	n.a.	n.a.	n.a.	n.a.
Household out-of-pocket payments as % of GDP, LTC Health	0.0	0.0	n.a.	n.a.
Household out-of-pocket payments as % of GDP, LTC Social	n.a.	n.a.	n.a.	n.a.

Source: Agency for Statistics of BiH, European System of integrated Social PROtection Statistics (ESSPROS) data.

Statistical Annex 2

Table A2.1 Services of care and assistance rendered at home, FBiH and RS (*Usluge njege i pomoci u kuci/domu, FBiH I RS*)

	2014	2015	2016	2017	2018
FBiH total	265	197	183	109	868
Minors	203	5	77	10	718
Adults	62	192	106	99	150
RS total	311	214	253	199	212

Source: RS Institute of Statistics (2019); Institute of Statistics for FBiH (2015, 2016, 2017, 2018 and 2019). In RS, data are not disaggregated for minors and adults.

Table A2.2 Professional employees in residential institutions for the elderly, FBiH and RS (*Strucno osoblje zaposleno u ustanovama socijalne zastite za odrasle, FBiH I RS*)

	2014	2015	2016	2017	2018
Healthcare personnel [professional and other], FBiH	318	417	469	515	497
Other professionally trained employees, FBiH	84	110	136	133	102
Healthcare personnel [professional and other], RS	166	169	219	228	285
Other professionally trained employees, RS	30	41	48	42	64
Total [both entities]	598	737	872	918	948

Source: Institute of Statistics for FBiH (2019, 2018, 2017, 2016, 2015 and 2014); RS Institute of Statistics (2019). Personnel classified as administrative and other have not been considered.

Table A2.3 Financing of some LTC-related rights, RS (*Finaniranje određenih prava iz oblasti dugoročne njege, RS*), in KM ('000)

	2014	2015	2016	2016	2018
Care allowance, total, municipalities	23252.8	27842.1	29473.9	33122.1	34436.7
<i>Co-financed from RS budget</i>	<i>12923.3</i>	<i>14351.6</i>	<i>15765.6</i>	<i>16791.4</i>	<i>17459.0</i>
In-house assistance, municipalities	299.7	330.9	342.0	333.8	305.6
Day care, municipalities	321.8	354.9	339.2	409.4	373.2

Source: RS Ministry of Health and Social Welfare (2015-2019), *Bulletins of Social, Family and Child Protection*.

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