Long-term care and palliative care

1) In your country/region, how is long-term care for older persons defined and provided for in legal and policy frameworks? What types of support and services are covered?

According to the official statistical data for 2018, the percentage of people over the age of 65 in Serbian population is 19.2 which means the needs for this type of services are high.[1]

Long-term care services for older people in Serbia are still fragmented and are scattered between the systems of social welfare, healthcare and pension insurance. This poses the problem of coordination and lack thereof. Statistics show that less than 10% of people over the age of 65 used some of the existing services. Total cost of long-term care services provided through the three systems is 0.53% of Serbian GDP which is notably lower than the European Union average. Currently, the estimation is that 90% of older people relies on family support for the most part.[2]

Social welfare system provides institutional services (residential home services), non-institutional services (home-based assistance, in 122 municipalities (total number of beneficiaries in 2015 was 20,474), foster care, clubs for older people in local communities and day care centers for older people, in seven municipalities) and cash and in-kind benefits (The cash benefits are means tested and recipients of cash benefits must be below the defined pension threshold. There is also allowance for support and care of another person). Residential home services are financed from the national budget with partial contribution by the beneficiaries. Club services as well as home-based assistance services are financed from municipal budgets. Welfare cash benefits are covered by the national budget while allowances for support and care of another person are provided by the pension fund and are available for persons with difficulties in performing the activities of daily living (77,000 people were receiving this allowance in Serbia in 2017). [3]

Even though the Law on Health Protection[4] treats persons over the age of 65 as a group in need of special attention due to the heightened health risk, at primary healthcare level only 40% of Health Centers in Serbia have the service of medical home care and they are targeting general population, not specifically older people.[5] Only in Belgrade there is a specialized healthcare institution targeting older people: Institute for Gerontology and Palliative care. Long-term medical care is also provided at secondary and tertiary healthcare levels through departments for prolonged medical treatment.

[1] http://www.stat.gov.rs/WebSite/Public/PageView.aspx?pKey=162
[2] Challenges in long-term care of the elderly in Central and Eastern Europe: http://www.ilo.org/budapest/what-we-do/publications/WCMS_532427/lang--en/index.htm
[3] Long-term care for older people in the social protection system in Serbia: http://probni.fpn.bg.ac.rs/wp-content/uploads/9-Natalija-Peri%C5%A1i%C4%87-%E2%80%93-Dugotrajna-za%C5%A1tita-starih-u-sistemu-socijalne-sigurnosti-Srbije.pdf
[4] "Official gazette of RS", no. 107/2005, 72/2009, 88/2010, 99/2010, 57/2011, 119/2012, 45/2013, 93/2014, 96/2015, 106/2015 and 113/2017: http://www.zdravlje.gov.rs/tmpmz-admin/downloads/zakoni1/zakon_zdravstvena_zastit.pdf
[5] Challenges in long-term care of the elderly in Central and Eastern Europe: http://www.ilo.org/budapest/what-we-do/publications/WCMS_532427/lang--en/index.htm

Civil society organizations also provide services in the community, such as home based assistance for older people, clubs for older people and they cover additional 20,000 people according to unofficial estimation.[6] The biggest burden still rests on families in providing this kind of care and assistance.

2) What are the specific challenges faced by older persons in accessing long-term care?

Main challenge is that the long-term care services are fragmented and scattered through multiple systems, which makes coordination and access much more difficult. A structured long-term model is needed with clearly defined funding sources.

The other challenge is the capacity of existing services. Only 10% of older population is covered by some of the existing services and, as an illustration, according to the 2016 report of the National Institute for Public Health 37.6% of older people in Serbia state that they have problems in performing daily activities independently.[7] Additionally, for rural and remote areas the accessibility of these services is significantly lowered. There is also insufficient number of geriatricians in Serbia.

The problem of insufficient access to formal services produces significant financial burden to older people and their families as they seek services on the informal labor market where providers of these services are completely unregulated, lack formal training and charge market prices. This affects financial security of older people who have needs for such services.

Finally, the capacity of support programs for informal carers (respite services and trainings) is currently insufficient.

3) What measures have been taken/are necessary to ensure high-quality and sustainable long-term care systems for older persons?

There are efforts to increase the capacity for provision of long-term care services in Serbia and while their capacity is on the rise it is still insufficient for the needs. One enduring issue is the problem of accessibility to services in smaller urban areas and rural areas and this still needs to be addressed.

The other problem, related to cash benefits and allowances is in the procedures necessary to provide the documentation that confirms eligibility for such support. These procedures are both time consuming and complex which decreases the probability of older people opting for this kind of support. Illustrating this is the fact that introduction of new procedures through the Law on Social Protection (2011)[8] lead to decrease of number of older people using these kinds of support.

With adoption of the Law on Social protection (2011) the process of licensing service providers to provide services of social care has started. The Law stipulates that all providers of social care services

[6] Mapping social protection services at local level in Serbia: http://socijalnoukljucivanje.gov.rs/rs/objavljeno-istrazivanje-mapiranje-usluga-socijalne-zastite-u-nadleznosti-lokalnih-samouprava-u-republici-srbiji/
[7] Institute for Public Health, Research on the health of the population in Serbia: http://www.batut.org.rs/download/publikacije/IstrazivanjeZdravljaStanovnistvaRS2013.pdf
[8] "Official Gazette of RS", no. 24/2011: https://www.minrzs.gov.rs/files/doc/porodica/Zakon%20o%20socijalnoj%20zastiti.pdf

must undergo training related to working with older people. The licensing covers both services provided at home as well as the residential care services. Still, the quality of services is uneven depending on the provider of the service.

One related problem to these services is the insufficient capacity to monitor the quality of provision.

There are procedures that address restrictive practices in residential care. The problem is that the oversight of these services is limited and the cases on record are few and far between. This does not mean that restrictive practices do not exist: for example use of sedatives without a clear indication is relatively frequent and this is primarily a problem because they are prescribed by medical professionals not specialized for work with older population.

There are procedures in place to report elder abuse in both public and private residential care institutions. The reported cases show a very low frequency of abuse in residential care and for the most part they are cases of abuse perpetrated by other beneficiaries rather than staff. This means that cases of abuse perpetrated by staff go unreported and that the abuse perpetrated by staff is unrecognized as such which is an even more serious issue. No independent study has been performed to date to explore this phenomenon.

When it comes to funding, it is sustainable in the current form but the current form of services is insufficient for the needs. The question is whether the funds exist to support increased accessibility to these services through introduction of a wider variety of services on offer (primarily in healthcare). It is essential to adopt a comprehensive long-term care model that would have clearly defined budget and funding sources.

4) What other rights are essential for the enjoyment of the right to long-term care by older persons, or affected by the non-enjoyment of this right?

Even though the legal framework in Serbia guarantees the right to access to health services, the fact is that services of long-term care and palliative care, especially non-institutional services, are not equally accessible to every person in need. First and foremost they are not equally distributed geographically, by being concentrated in larger cities and being less accessible to residents of rural areas. In some communities they are non-existent whereas in other communities they are formally available but long waiting lists make them harder to access for a part of population. Older persons who do not have family members in their place of residence and who do not have sufficient income to pay for the services on the market are especially at risk as this creates further inequalities in access to health.

Serbian Commissioner for Protection of Equality has in February 2018 sent a recommendation to the Ministry of Labor, Employment, Veteran and Social Policy as well as the Ministry of Health to improve the systems of palliative care and long-term care. The Commissioner did this as a response to complaints sent by older citizens and civil society organizations, raising the issue of discrimination of persons over the age of 65 in need of health services to which access has been granted by law.

5) In your country/region, how is palliative care defined in legal and policy frameworks?

Palliative care services are defined through National Strategy of Palliative Care (2009)[9] and the related Action Plan[10] and it is implemented at primary health care level, mostly focusing on home treatment and outpatient treatment. At secondary and tertiary level there is a certain number of beds for palliative care services. At primary healthcare level the Strategy envisions cooperation between multiple sectors so teams for palliative care include general practitioner, nurse, patronage nurse, physiotherapist and social worker. Extended versions of this team include a psychologist, a psychiatrist, a priest and volunteers.

The Rulebook on terms and Conditions for Performing Healthcare Activities in Healthcare Institutions and other forms of Healthcare is another document regulating this area. The whole framework is based on holistic approach including different support systems and experts from different sectors.

One issue worth mentioning is that the Action Plan for the National Strategy of Palliative Care has expired in 2015 and currently it is unknown when the new one will be developed.

6) What are the specific needs and challenges facing older persons regarding end-of-life care? Are there studies, data and evidence available?

The capacity of existing services is insufficient and there are problems in coordinating different sectors that are working together on provision of these services. Although there is legal and strategic framework for palliative care and the Law on Social Protection stipulates development of health and social care institutions, the implementation is lagging.

The Strategy of Palliative care does not explicitly mention dementia in the context of palliative care. This can lead to difficulties in accessing the services of palliative care.

Another problem relates to data collection as there is not a sufficient number of studies on the needs of palliative patients, or evaluations of the efficacy of the existing set of palliative care services.

Partially the problem is with the law that stipulates that general practitioners are supposed to provide home treatment and palliative care services but they lack capacity and sufficient time to provide them. Also, there is a shortage of medical nurses in the system that is supposed to provide these services.

7) To what extent is palliative care available to all older persons on a non-discriminatory basis?

[9] "Official Gazette of RS" no. 55/05, 71/05, 101/07 and 65/08: http://www.zdravlje.gov.rs/downloads/Zakoni/Strategije/Strategija%20Za%20Palijativno%20Zbrinjavanje.pdf

[10] Action plan: http://www.zdravlje.gov.rs/downloads/Zakoni/Strategije/Strategija%20Za%20Palijativno%20Zbrinjavanje%20Akcioni%20Plan%202009-2015.pdf

The main problem is that of access to services. More than 40% of health centers across the country do not provide home treatment and care services.

8) How is palliative care provided, in relation to long-term care as described above and other support services for older persons?

As mentioned above long-term care services are fragmented and scattered among three different systems. As for palliative care, it is mostly under the responsibility of Ministry of Health. Where they overlap is in the services of home treatment and care as well as in secondary and tertiary healthcare institutions at departments for prolonged medical treatment. Since the services are not defined clearly, their efficiency is somewhat diminished. The problem of both long-term care and palliative care services is insufficient coordination and oversight.

9) Are there good practices available in terms of long-term care and palliative care? What are lessons learned from human rights perspectives?

Institute for Gerontology and Palliative Care, Belgrade is a specialized medical institution referent for extra-institutional (community based) health care of older people. The Institute is conceived as a health care establishment for the older adults and implementation of measures for health improvement and prevention of diseases characteristic for this population, including home treatment and nursing, palliative care and rehabilitation of the older people. The Institute also represents educational base for postgraduate studies in gerontology and specialization in general practice at the University of Belgrade, School of Medicine, and also for the Nursing College in Belgrade.

The Institute works closely with the CSOs and local self-governments on improving different modes of care for older people, through a large number of trainings arranged for the volunteers and home treatment personnel in Serbia.

The focus is on improvement of community based health care/ home care of older adults by keeping pace with the latest world practice in this field, through permanent education of all employees and procurement of modern equipment for the best quality of service. The Institute works both on building relations and partnerships with all relevant organizations and entities, including older adults as equal partners, and developing new services and modes of health care and care for the older adults, which will contribute to higher quality of life for older people.

Another example is the Gerontological Center Belgrade, an institution for social protection licensed to provide residential services through four homes for older people, home based services at the whole territory of the city of Belgrade, day care services (12 hours per day on workdays) and 26 clubs for active ageing. The Centre provides services related to primary healthcare, nutrition, legal support, psychological support, occupational therapy, hairdressing, physiotherapy and assistance with maintaining personal hygiene. Gerontological Center Belgrade is the first institution for social protection in Serbia that was licensed for residential care and home care services by the Ministry of Labor, Employment, Veteran and Social Policy in 2013.

These are examples of good practice because these institutions have well-structured and clearly defined services and responsibilities, they have trained staff, guaranteeing the quality of services delivered. The Gerontological Center Belgrade also partly relies on the participation of beneficiaries in the design of some of its services. These examples show that well-structured services with well trained staff and participation of beneficiaries ensure better and more equal access, thus better protecting older people's rights.

In future, introduction of a well-defined long-term care model will be advocacy goal of the civil sector in Serbia as well as part of the efforts of the Commissioner for Protection of Equality.

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