

LONGTERM CARE AND PALLIATIVE CARE

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

The Law on Social Welfare¹ stipulates the home accommodation as one of the social welfare services (Article 40, paragraph 1, item 5). The Article 41, paragraphs 1 and 3 of the Law on Social Welfare, stipulates that “social welfare services beneficiary shall be an individual or a family facing obstacles in meeting their needs which prevents them from attaining or maintaining life quality or lacking sufficient financial funds to meet their basic life needs being unable to do so through work, asset revenues or other sources.”

“Persons who have reached the age of majority and are over 65 (hereinafter referred to as: the elderly beneficiaries) are the beneficiaries within the meaning of Paragraph 1 of this Law, when their welfare, safety and productive life in a society is jeopardized by risks due to old age, disability, illness, family-related or other life circumstances and in particular:

- 1) if they have physical, intellectual, sensory or mental difficulties or difficulties in communication, and when faced with functional limitations in one or more areas of life due to social or other obstacles;
- 2) if there is the danger that they would become or have become the victims of self-neglect, neglect, abuse, exploitation and domestic violence;
- 3) if they are faced with difficulties due to dysfunctional family relations, addiction to alcohol, drug or other intoxicants or other forms of socially unacceptable behavior and other causes;
- 4) if they are victims of human trafficking;
- 5) if they are foreign nationals and stateless persons in need of social welfare;
- 6) if they need a home accommodation or other needs for using social welfare

Accommodation services specified by this Law shall be provided by accommodating the beneficiary 1) in a kinship, foster and other family for the adults and the elderly (hereinafter referred to as: family accommodation); 2) residential social home institutions for accommodation of the beneficiaries, including small home communities (hereinafter referred to as: the home accommodation); 3) shelter; 4) other types of accommodation pursuant to the Law. The accommodation shall be provided by the Republic of Serbia, the Autonomous Province and the local self-government unit in accordance with this Law (Article 47 of the Law).

Home accommodation shall be provided, inter alia, as: 1) standard accommodation 2) accommodation with intensive or additional support.

¹ Official Gazette of RS” No. 24/11.

Detailed conditions for the use of the home accommodation service and other types of home accommodation shall be prescribed by the Minister competent for the social protection operations² (Article 53 of the Law).

Home accommodation services may be provided by a social welfare institution i.e. a provider of social welfare services that has been licensed for providing these services. A home accommodation facility for adult and elderly beneficiaries cannot have a capacity of more than 100 beneficiaries and home accommodation facility for children and the young cannot have a capacity of more than 50 beneficiaries (Article 54).

The Law on Social Welfare stipulates services in the community which include activities supporting the beneficiary's stay in the family and the immediate surroundings. Day care services in the community shall be provided by the local self-government unit (Article 44). Furthermore, the support services for independent living rendered to the individuals are planned in order to make their possibilities for meeting basic needs equal with the possibilities of other members of the society, to improve their quality of life and to enable them to have an active and independent social life. These services shall be provided by the local self-government unless the Law states that they shall be provided by the Republic of Serbia. (Article 45)

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

The needs for home accommodation exceed the availability, thus the cases of overcrowdedness and wait lists are frequent. A significant number of beneficiaries of homes for the elderly have been placed in homes without their consent, but with the consent of their children or a close relative, even if the persons being placed in this institution have not been deprived of their occupational ability. There are still illegal homes for the elderly which do not meet the prescribed work requirements, appropriate licenses and work permits, whose incompetent and uncontrolled work regularly violates the guaranteed rights of the elderly beneficiaries placed in these institutions.

3. *What measures have been taken /are necessary to ensure high quality and a sustainable long-term care systems for the older persons, including for example:*

- *Sufficient availability, accessibility and affordability of services on a non-discriminatory basis?*
- *High quality of services provided?*
- *Autonomy and free, prior and informed consent of older persons in relation to their long-term care and support?*
- *Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in the long-term care?*
- *Sustainable financing of long-term care and support services?*
- *Redress and remedy in the case of abuse and violations?*

² The Rulebook on Detailed Conditions and Standards for Extending Social Welfare Services, Official Gazette of the Republic of Serbia No 42/13.

Social Welfare Development Strategy³ defines the critical objectives in this area which are, inter alia, guaranteeing the appropriate social welfare level, securing the welfare of the most vulnerable social groups, as well as prohibiting social exclusion and discrimination. This Strategy specifies individual objectives and measures, activities and mechanisms for their achievement. When it comes to measures for improving the quality of accommodation and care services, the Protector of Citizens has noticed in its work that the lack of financial means is one of the main and the most frequently stated reasons owing to which the capacities of homes are not sufficient, the accommodation conditions are not on an adequate level and the institutions are understaffed. In connection with the subject matter, we note that the Protector of Citizens sent the Opinion on the Proposal of the Strategy for Improving the Position of Persons with Disabilities in the Republic of Serbia by 2020 to the Ministry of Labor, Employment, Veteran and Social Policy having in mind the fact that among persons with disabilities (physical and mental) in residential accommodation there is a significant number of the elderly beneficiaries. The Protector of Citizens has recognized in his work that a large number of home beneficiaries have been placed in homes without their own consent, but with the consent of their children or closest relatives, even if persons placed in these institutions are not deprived of their occupational abilities. There still exist illegal homes for elderly people without license or work permit whose incompetent and uncontrolled work heavily violates the guaranteed rights of the elderly beneficiaries accommodated in these institutions. In the event of a person experiencing abuse and violence in the institutions, there is a mechanism for the protection of rights through appropriate court proceedings. However, the timely report of violence and responding to it may be a problem since these persons are often powerless, with serious health problems and some of them have no relatives to come to visit and report violence. What we want to highlight is that the Protector of Citizens handled the complaints of the relatives of the residential accommodation beneficiaries and required the Social Welfare Inspection to conduct supervision. In this regard, the Protector of Citizens has established a sound cooperation with the competent Inspectorate in the Ministry of Labor, Employment, Veteran and Social Policy. Furthermore, the Protector of Citizens and the National Preventive Mechanism, during their regular visits to the social welfare institutions, observe the situation and the protection of rights of persons from abuse and neglect.

When it comes to the restriction measures, such as retention, seclusion, chemical and physical restraint, we emphasize that there is a basis for such treatment in the Law on Social Welfare and hereby we emphasize that the Ministry of Labor, Employment, Veteran and Social Policy when responding to the Report of the Protector of Citizens – National Preventive Mechanism for 2014, pointed out that the Rulebook on Prohibited Behavior of Employees in the Area of Social Welfare⁴ clearly specifies the prohibited behavior of employees in reference to the beneficiaries.

In addition, through control mechanisms, the Ministry obliged all the accommodation institutions to adopt internal procedures for the implementation of measures and actions for

³ Official Gazette of the RS, No. 108/05.

⁴ Official Gazette of the RS, No. 8/12

restricting movement, isolation or controlling the behavior of the beneficiary pursuant to the Law on Protection of Persons with Mental Disabilities⁵.

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

The lack of a timely and quality long-term care service at the risk of injury or threat is the right of a person to adequate care, safe keeping, health care and meeting basic living needs.

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

Palliative care is part of the Law on Health Care ⁶ and it is planned as one form of the health care provided by the health care activity at the primary level (Article 88, paragraph 1, item 12 of the Law). In addition, the Article 39, paragraph 2 of the Law on Health Insurance⁷ stipulates that an insured person who is in a terminal stage of an illness. immobile or mobile with the help of other persons and in need of palliative care, is entitled to short-term hospital treatment for the application of symptomatic treatment and health care, under the conditions specified in the General Act of the Republic Fund.

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

The lack of accommodation capacities in hospitals for palliative care of the elderly persons, as well as the persons suffering from the most serious diseases are the challenges owing to which they are frequently placed in the homes for the elderly.

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

Positive legal regulations secure the access to services from the areas of health care and social welfare on equal basis.

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

Under certain conditions, palliative care is provided in hospitals as stated above, in the social welfare institutions (homes for elderly people and homes for persons with disabilities) and in the institutes. The Law on Health Care delineates institutes as health institutions which perform

⁵ Official Gazette of RS No. 45/12

⁶ Official Gazette of the Republic of Serbia 107/05, 72/09, - other law 88/10, 99/10, 57/11, 119/12 45/13, - other law 93/14, 96/15 and 106/15-other law.

⁷ Official Gazette of the RS No. 107/05, 109/05 - corrigendum 57/11, 110/12 - Decision of the Constitutional Court, 119/12, 99/14, 123/14, 126/14 - Decision of the Constitutional Court , 106/2015 и 10/2016 -other Law.

health care activity on a primary level and conduct health care of certain population groups or the health care activity from a specific health care area.

An institute is founded, inter alia, as the institute both for gerontology and palliative care. As an example, we can mention the Institute for Gerontology and Palliative Care in Belgrade which has existed since 1987 and it has been founded by merging the Institute for Chronic Diseases and Gerontology and the Center for Home Care.

As a specialized health care institution on a primary level of health care, the Institute performs outpatient and social-medical health care activity targeting the population group of functionally dependent and gravely ill citizens of Belgrade aged 65 or more. Within the Institute, there is a Service for Home Treatment and Care.

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

A good practice of the above mentioned Institute for Gerontology and Palliative Care in Belgrade which published a study *The Gerontology in Serbia in 2013* is available. From the perspective of human rights, it is vital that the country recognize the need and take steps with the aim of founding new specialized institutions which would be intended exclusively for the palliative care of the elderly and the ill in the terminal stages of their illness. This is particularly important if we consider the fact that in Serbia over the last 15 years there is a huge increase in the rates of the ill and deceased from carcinoma. The patients in the terminal stages of the disease and their families are most frequently faced with the lack of care in the health care institutions, they spend their last days at home, instead of being in a hospital and members of the family look after them which is a huge challenge with extremely negative consequences for both the emotional and psychological state.