

Contribution of Slovenia

Autonomy and independence

1. In your country/region, how is the right to autonomy and independence of older persons defined in legal and policy frameworks?

Autonomy is not defined within any Slovene legal rules *per se*. However, autonomy is implied and guaranteed under the Slovene Constitution as well as various legislative acts. It is important to note that autonomy is also guaranteed under international human rights conventions ratified by the Republic of Slovenia.

Article 14 of the Slovene Constitution guarantees everyone equal human rights and fundamental freedoms irrespective of any personal circumstance. Thus it safeguards before breaches of autonomy which are usually observed in relation to personal circumstances, such as old age and disability. Article 19 of the Slovene Constitution guarantees everyone the right to personal freedom. Further, Article 21 of the Slovene Constitution gives everyone respect for human personality and dignity in criminal and in all other legal proceedings, as well as during the deprivation of liberty and enforcement of punitive sanctions. This is especially important in the context of deprivation of liberty of persons suffering from mental disabilities, such as persons with dementia whose freedom is restricted in special units of care facilities. In such cases, every detained person has the right to appeal to an independent, impartial court constituted by law (Article 23 Slovene Constitution).

Article 22 of the Constitution also partially touches on this area as it guarantees equal protection of rights of everyone in any proceeding before a court and before other state authorities, local community authorities and bearers of public authority that decide on his rights, duties or legal interests.

In terms of national legislation, there is no specific legislative act addressing older persons generally or their autonomy and independence specifically. Social care provided to older persons is governed by the Social Assistance Act and various subordinate rules. The Slovene Mental Health Act includes provisions on deprivation of liberty governing the treatment of (all not just older) persons requiring mental health treatment. The Patient Rights Act determines a patient's right to take part in decision-making regarding their medical treatment and the right to be actively involved in the choice of treatment.

The majority of specialised institutions and care homes for older persons have closed wards. Admission into these wards and rights of individuals during their stay there is addressed in the Mental Health Act. Supervision over the work in such wards is carried out by *inter alia* the national preventive mechanism.

2. What other rights are essential for the enjoyment of the right to autonomy and independence by older persons, or affected by the non-enjoyment of this right?

Human rights are interrelated and interdependent. We would argue that the right to autonomy is essential for enjoyment of all human rights. If older persons are (unjustly) deprived of their autonomy and independence then they cannot possibly be fully included in the society.

Important factors for anyone and older persons in particular, to enjoy the right to autonomy and independence are income security and the accessibility of health care. The Health Care and Health Insurance Act provides full coverage of all medical treatment expenses for persons above the age of 75 with compulsory health insurance.

Other areas key to the enjoyment of the rights to autonomy and independence are:

- ensuring working conditions that enable extension of working life,
- providing access to education and training,
- improving of general health, decreasing inequalities in health,
- adapting social protection systems to demographic changes,
- ensuring good quality of life for families (informal carers in particular need to be able to adjust their professional and private life),
- the use of ICTs,
- preventing of ageism, discrimination and violence against older persons,
- encouraging hobbies, cultural activities, sport,
- encouraging political and civil engagement,

- adapting living environments.
- adapting transport and transport infrastructure.

3. What are the key issues and challenges facing older persons in your country/region regarding autonomy and independence? What studies and data are available?

There is a lack of empirical large cohort studies in the field of older persons' autonomy. Association of Social Institutions of Slovenia suggested a need for a reform of relevant social care acts to ensure that the rights of older persons are acknowledged and protected. They further questioned the issue of guardianship of an older person, especially the lack of safeguards against abuse, particularly if the older person loses his or her legal capacity. They proposed using good practices which use Power of Attorney as a way to assure that persons' will is abided even after they cannot make rational decisions about their health care or other aspects of life anymore (legal matters, finances etc.).

Autonomy and independence need to be approached in a wider context as they are affected by many factors (including the question of long-term and palliative care). One important challenge Slovenia is facing is the growing incidence of suicide among older persons in recent years. Declining autonomy and independence might be contributing factors in this development.

4. What steps have been taken to ensure older persons' enjoyment of their right to autonomy and independence?

In terms of legislation, the Slovene Mental Health Act provides for judicial review when older persons suffering from mental health problems are detained in social care institutions.

We have a Code of Medical Ethics by which doctors are obliged to always respect patient's will, even in the past expressed will in written or oral form of a patient who no longer can make rational decisions but was able to make them at the time of stating his last will (Article 15).

National Preventive Mechanism of the Republic of Slovenia carries out visits to places of detention, nursing homes, psychiatric hospitals etc. upon initiatives.

Inspection for social affairs performs not just regular and periodic inspections but also exceptional inspections.

Resolution on the national mental health programme 2018-2028 was adopted by the National Assembly in March 2018. One of its goals is the strengthening of the network of mental health service providers in the community as the precondition to deinstitutionalization.

5. What mechanisms are necessary, or already in place, for older persons to seek redress for the denial of autonomy and independence?

Since autonomy and independence are mentioned in different laws and regulations (for example the Patient Rights Act or Mental Health Act or Social Assistance Act), the petitioner has to follow the complaint procedure according to that law. Many might also firstly think of addressing their complaint to Ombudsman who may then direct them to appropriate procedures.

6. What are the responsibilities of other, non-State, actors in respecting and protecting the right to autonomy and independence of older persons?

Their role is in informing the public about injustices, pointing out problems that people face, offering (legal) counselling, advocacy and dissemination of good practice. Representatives of older persons are included in the process of formulation of national policies, drafted to address the demographic ageing. The position of the deputy chair of the governmental Council for Active Ageing and Generational Solidarity is reserved for the representative of the Slovene Federation of Pensioners' Associations as the largest national NGO dedicated to the well-being of older persons.

Contribution of Slovenia

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?

In Slovenia, there is no valid uniform definition of long-term care (LTC), neither is the area systematically regulated (e.g. by a special act). Currently, LTC is regulated within the framework of different legislation and is provided via separate social protection systems, namely:

- pension and disability insurance, i.e. the Pension and Disability Insurance Act (hereinafter: PDIA-2),
- health insurance, i.e. Health Care and Health Insurance Act,
- parental protection insurance, i.e. Parental Protection and Family Benefit Act,
- social benefits and social welfare services, i.e. Social Security Act, Financial Social Assistance Act and Exercise of Rights to Public Funds Act,
- care for war veterans, i.e. War Veterans Act and War Disability Act, and
- within the Act Concerning Social Care of Mentally and Physically Handicapped Persons.

Considering the current regulation of LTC one can say that, in Slovenia, it is provided in different ways, i.e. through diverse services from the area of social welfare and health care and through cash benefits. For a number of years, the umbrella act that would regulate the area of LTC has been in the process of preparation. Drawing up different versions of the acts and numerous discussions in the expert public reflect a great pressure, need and appeal to systematically regulate this area. In 2008, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, in the National Report on Strategies for Social Protection and Social Inclusion 2008–2010, identified several deficiencies of the existing system, *inter alia*, that:

- the existing services and cash benefits are not linked in a uniform system;
- in practice, there is a lack of smooth coordination between different service providers, thereby hindering access to the services and reducing their quality;
- the user is not always provided with quality, equal and needed access to services;
- home-based services are still undeveloped, which causes additional pressure to prolong the expensive hospitalisation and expansion of institutional forms of LTC.

The policy framework provided in the National reform programme 2016-2017 included the commitment of the government to formulate a more efficient and user friendly LTC services and benefits system. Other strategic social and health policy documents included efforts to ensure equal access to quality LTC services, to integrated and comprehensive approach and to take into account the changing needs of the ageing population. A timely adoption of an act on LTC is important from the viewpoint of sustainability of social protection systems as well as from the viewpoint of equal accessibility and availability of services to LTC users, regardless of whether they remain in the home environment or they are placed in an institution.

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

LTC is still not properly regulated in our legislation.

Among the particular issues that have been identified in Slovenia as challenging in access to LTC are:

- Too many different government and non-government agencies are responsible for (overlapping) provision of LTC services; and
- the evident lack of transparency, because of different entry points and different needs assessment procedures, resulting in access to care being uneven, and at times inequitable.

The consequences of these issues include some (substantial but hard to quantify) unmet needs, some inefficient use of existing LTC resources, unnecessary burdens on families both in terms of providing care and in helping navigate the system, difficulty in planning for the growing needs and difficulty in building quality and standards into care provision.

Help at home is still not available in all Slovene municipalities; in less than a third of municipalities it is available only on workdays. Moreover, the price of the services differs among municipalities. The service of telecare has also never really been implemented and is too expensive in its current form, as it is

organized independently of public sector network. By placing it among the services of public sector network, the costs of telecare for the user would decrease.

Some key characteristics of the current system in Slovenia were also stated in the report “Adequate social protection for long-term care needs in an ageing society 2014” by the Social Protection Committee and the European Commission:

- The existing services and benefits are not connected within a uniform system, making access to services harder and their quality and transparency poorer. Different rights are regulated by different acts in various fields. There are different entry points and different procedures for assessing needs. The existing regulation sometimes puts users in an unequal position and some are even excluded from the system, causing unequal treatment of individuals with comparable needs.
- Institutional care is still predominant and is also based on the so-called medical approach. But this system is not diverse enough, because it does not consider individual needs of users.
- One of the problems is also regional access and a difference between cities and the rural area in sense of access to services. The offer of formal services is poorly developed in the local environment.
- There is a distinction between health care and social care services in the context of community long-term care and care in the home environment (need for coordination and unification).
- The present regulation is predominantly curative; there is not enough emphasis on rehabilitation and prevention; using information and communication technologies in long-term care is not widespread enough.
- Besides systemic reasons, also demographic, fiscal, economic and social reasons are important for reforming the current long-term care system.

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

- **Sufficient availability, accessibility and affordability of services on a nondiscriminatory 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 long-term care?**
- **Sustainable financing of long-term care and support services?**
- **Redress and remedy in case of abuse and violations?**

All of the above have to be addressed at one in order to provide LTC. The problem which we mostly face is creating sustainable financing along with accessibility and affordability of services.

Proposed measures and activities, prepared in Active and Healthy Aging project¹:

- The activities of long-term care, its means of funding, network and organisational framework need to be legally defined at the national level.
- In order to ensure financial sustainability of the system, a realistic estimation of the need for long-term-care services has to be prepared and the most optimal way of funding has to be determined.
- The role of municipalities or local communities in providing long-term care has to be legally defined, and the concept 'local environment' has to be formulated in the context of long-term care implementation (a municipality, several municipalities, a region etc.).
- To legally define the working position of local area coordinator and his or her role in long-term care activities.
- To establish a system of quality, protection and control.
- To establish a systemic informational support for the implementation of long-term care activities and user support informational system.
- To give greater support to informal carers.
- To encourage volunteer work as an additional source of providing services for older people and to implement organized volunteer work.
- To make an analysis of current and potential user needs and prepare suitable programs on the basis of identified needs at the local level.
- Timely and flexible response to user needs.

¹ http://staranje.si/sites/www.staranje.si/files/upload/images/m20_aha_si_dolgotrajna_oskrba-ang.docx.pdf

The last draft of LTC act was prepared in 2017. It aims to establish a comprehensive integrated LTC system for users that require it due to illness, age, injury, disability etc. The draft act was in public debate in October and November 2017. On the basis of the received comments and public response further work on the draft is required. Key aims of the draft act are:

- to unify the legislation addressing LTC services;
- to define LTC;
- to formulate a set of LTC services and rights;
- to formulate unified criteria for inclusion in LTC system;
- to formulate a comprehensive, universally accessible, financially sustainable and available LTC system;
- to enable a user to remain in home care as long as possible, if he/she desires it;
- to support providers of informal care in home environment;
- to provide respite care;
- to place user at the centre of the LTC system;
- to manage the increase in private provision of LTC services, which could increase the risk of poverty, especially among the older population;
- to improve the planning, management and ensuring quality, safety and efficiency of LTC provided as public service; and
- to establish efficient public oversight of LTC services provision.

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?

LTC accessibility should be a right of every older person and in compliance with the principle of non-discrimination and equal treatment. In order for all users to enjoy the right to LTC it is key to, *inter alia*, ensure universal accessibility to quality LTC services and sustainable financing of LTC system as well as support informal caregivers.

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

We currently do not have a specific law regulating palliative care. Instead we logically abide by other legalisation which indirectly includes palliative care.

For example article 39. of the Patient Rights Act speaks of patient's right to receive whatever help needed to eliminate the pain or other suffering because of the illness, or to ease it as much as possible. According to this article patients in final stage of the illness and patients with incurable disease which causes severe suffering has the right to receive palliative care. Additionally, the Patient Rights Act provides the right to complain about violations of patient's rights and the right to assistance in realising patient's rights free of charge.

A national plan of palliative care development was adopted in 2011. There are also certain laws which include the right of palliative care as a basic patients' right (Patient Rights Act, Medical Chamber's Code).

The national cancer control programme addresses the palliative care of patients with cancer. A awareness-raising programme Metulj was formulated to inform the public on the options and challenges of palliative care.

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

There is a certain lack of comprehensive national studies on the specific needs and challenges facing older persons regarding palliative care. The purpose of palliative care is to improve and sustain the quality of persons' lives and their relatives', to relieve their pain and to meet their needs, not only physical but also psychological, social and spiritual.

In October 2017 the National Council of the Republic of Slovenia and the Human Rights Ombudsman organised a public consultation to discuss end-of-life issues from the humanistic, legal and medical viewpoint. One of the challenges outlined in the context of palliative care was access for neurological patients with severe neurodegenerative diseases such as Alzheimer's or Parkinson's disease. Such patients might lack the ability to efficiently communicate their pain, spiritual suffering, suicidal thoughts etc. in the advanced stages of their disease. Another challenge is overcoming the taboo in discussing death and dying in order to assist patients in coming to terms with their diagnosis and making timely informed decisions

regarding their medical treatments. An issue that also requires considerations is support for the informal caregivers.

The Slovenian Palliative and Hospice Care Society identified the following challenges in formulating a system of palliative care:

(1) Formulating palliative care as a priority: Taking into account the increasing incidence of malignant and neurodegenerative diseases associated with ageing populations, the public health system needs to be organised accordingly.

(2) Deciding who and when should be included in palliative care: Palliative care is mostly provided to patients with cancer and much less in case of other chronic terminal diseases, mostly because of the lack of clear criteria for inclusion, but also due to a lack of qualified staff and other capacities. In the case of older patients who might have several chronic ailments, a comprehensive approach is required.

(3) Access to multidisciplinary treatment: Addressing accessibility through establishing an appropriate network of palliative care.

(4) Education: Including palliative care in educational programmes in relevant graduate and post-graduate education.

(5) Visibility of need for palliative care on the side of the patients as well as on the side of providers of medical care.

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

Every Slovenian citizen who is insured has the right to palliative care services. Since palliative care is subject to other laws and regulations, those provisions also apply to palliative care.

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

Palliative care is part of the Slovenian health care and social care system. It is provided in the institutions (such as hospitals, primary health centres, institutional care centres), at home and in the form of mobile unit as basic and specialized care and in some cases with assistance from NGOs. Social welfare institutions are included in the State programme of palliative care (2010) and the Resolution on the National programme of social care in the period 2013-2020 as providers of palliative care.

Some of the care homes for older persons provide palliative care as part of institutional caretaking, especially for patients with advanced dementia. Persons with such condition require adapted palliative care, taking into account that it was first developed specifically for cancer patients.

In addition to the palliative care programmes in institutional care and those provided by health teams, a programme of comprehensive hospice care is provided by the NGO Društvo Hospic.

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

We do have a hospice house which is dedicated to palliative care and support for the patients and their relatives. As mentioned earlier, a person has the right to pass with dignity and in no pain or as little as possible.

With the introduction of a mobile palliative care unit, a good connection has been established between the primary and secondary/tertiary levels. People tend to stay at home; it has become a value to be cared at home and to die at home.

Good practice 1: National point for the elderly – the Matija network

MATIJA connects and supports volunteer and other organisations and service providers and providers of goods for older people. The network is available through a uniform phone number. Source: <http://www.cd-matija.si/kdo-je-matija>

Good practice 2: HELPS project (housing for the elderly)

Housing and Home-care for the Elderly and vulnerable people and Local Partnership Strategies in Central European Cities – an international project for the accommodation of older people that is cofinanced by the Central Europe programme from the European regional development fund. Within this project, a

counselling office for better living conditions of the elderly was established Ljubljana. Source: <http://www.zdus-zveza.si/helps>

Good practice 3: The elderly for a better quality of life at home

In 1995, retired professionals of the Slovenian Philanthropy and the Slovenian Federation of Pensioners' Organisations started to develop a project on mutual assistance of the elderly so they could stay in home care as long as possible.

Source: <http://www.zdus-zveza.si/starejsi-za-visjo-kakovost-zivljenja-doma>

Good practice 5: Young people for the young at heart – an intergenerational cooperation project

The regional Red Cross Organisation in Novo mesto organised the project Young people for the young at heart in 2012 (European year of active ageing and intergenerational solidarity). This project stresses the importance of active ageing and intergenerational connections.