**GUIDING QUESTIONS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP OF AGEING**

**Long-term and Palliative Care**

**National legal framework**

1. What are the legal provisions in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?

The legal framework that defines the long-term treatment of the older person is given by Article 12 of the Inter-American Convention on the Protection of the Human Rights of Older Persons (CIPDHPM), which establishes that the right to "the protection and promotion of health, coverage of social services, food and nutrition security, water, clothing and housing; promoting that the older person can decide to remain in their home and maintain their independence and autonomy" Law 27,360 ratified the CIPDHPM.

Article 2 defines "Palliative Care" as the active, comprehensive and interdisciplinary care and treatment of patients whose illness does not respond to curative treatment or suffer from avoidable pain, in order to improve their quality of life until the end of their days. It implies a primary attention to the control of pain, other symptoms and the social, psychological and spiritual problems of the older person. They cover the patient, their environment and their family. They affirm life and consider death as a normal process; they do not accelerate or delay it.

On the other hand, the 26529 Law of Patient Rights in its Relationship with Health Professionals and Institutions (as amended by Law 26742) establishes in article 5, point H, "the right to receive comprehensive palliative care in the process of care of your illness or condition.” Its regulatory decree defines palliative care as" the multidisciplinary care of the terminal patient destined to guarantee hygiene and comfort, including pharmacological or other procedures for the control of pain and suffering ".

In relation to palliative care, the National Program of Palliative Care (resolution 1253-E / 2016 of the Ministry of Health of the Nation) exists within the framework of the National Cancer Institute of the Ministry of Health and Social Development, whose objectives are: a) the promotion of continuous and integrated care for all oncological patients throughout their illness, with special emphasis on preventing suffering and improving their quality of life and that of their families. b) The achievement of pain relief and access to opioid medication is an effective reality for all patients in the country, eliminating accessibility barriers for these drugs.

Resolution 934/2001 of the Ministry of Health of the Nation, establishes the Standard of Organization and Operation in Palliative Care, (modifying the previous Resolution No. 643/00) within the framework of the National Program of Quality Assurance of Medical Care.

In it there are some important references regarding the conceptual framework of palliative care and the insertion of the caregivers of the included patients:

* Referring to Technical Report 804 of the World Health Organization (1990), it states that: "Palliative Care is the active and total assistance of patients and their families by a multi-professional team, when the patient's illness does not respond to the healing treatment "
* It also establishes a series of general objectives of palliative care, among which we note especially, for the purposes of this course, the following:

• Detection and evaluation of the physical, psychological, social and spiritual needs of people with advanced disease, progressive despite instituted treatments, incurable and potentially fatal in the short or medium term.

• Promotion and implementation of interdisciplinary strategies for patient and family care aimed at providing well-being and quality of life until the end of life.

• Promotion of detection systems and prevention of sequelae in the family and / or in the significant environment.

• Organization and execution of measures to prevent exhaustion symptoms in professional or non-professional caregivers.

• Organization of treatment strategies for healthcare teams in the presence of symptoms of exhaustion in their members.

The Obligatory Medical Program (OMP), that establishes the benefits that should be provide, at least, by the National Social Works and the prepaid medicine companies, includes palliative care from Resolution 201/2002 of the Ministry of Health of the Nation, which establishes in the paragraph referred to the subject:

"8.1. Palliative care is the active and total assistance of patients by a multidisciplinary team, when the life expectancy of the patient does not exceed the period of 6 months, for not responding to the curative treatment that was imposed. The objectives here will be to alleviate the pain, the symptoms and the psychosocial approach of the patient. The coverage will be given according to the general framework established by the PMO, that is to say that the Agents of Normative Update Nº 1/2002 - SSSALUD 5 are obliged to provide the services mentioned in Annexes II and III with a 100 % coverage. "

That is to say, both the Social Works of the national system (those included in Laws 23,660 and 23,661, commonly known as "national social works" or "social union works") and the companies of prepaid medicine must finance the palliative care benefits.

Palliative Medicine is recognize as a specialty based on Resolution 1814/2015 of the Ministry of Health.

On the other hand, the National Directorate for Policies for Older Adults (DINAPAM), a body dependent on the National Secretariat for Children, Adolescents and the Family of the Ministry of Health and Social Development, is in charge of the country's gerontological public policies and is responsible for implementation of care training policies and the management of 8 long-stay residences. In this sense, it provides direct assistance to older people who require long-term care and does so under the rules of the Regulation for Long-term Residences for Older Persons (Resolution N ° 612-2015) which establishes the rights and obligations of the residents as well as the teams and the coexistence guidelines.

**Normative elements**

2. What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.

The key elements of the regulations on the subject are based on the existence and the obligatory nature of the informed consent established in Chapter III of Regulatory Decree 1089/2012 of Law 26529 and Modifying Law 26742. The right to informed consent is contemplated in the Civil and Commercial Code.

3. How should long-term care and palliative care be legally defined?

There is a set of standards of different levels, that establish a regulatory framework for the formation of teams and the development of specific activities.

Resolution 934/2001 of the Ministry of Health of the Nation; Resolution 201/2002 of the Ministry of Health of the Nation that includes palliative care in the Compulsory Medical Program (PMO). There, the benefits are established on the benefits floor that must be provided by the National Social Works and the prepaid medicine companies.

**Implementation**

4. What are the policies and programs adopted by your country to guarantee older people's enjoyment of their right to long-term and palliative care?

One of the most important policies regarding long-term care and palliative care is given by the training in gerontological care for older people from a human rights perspective and in person-centered care. In this line, the progressive attention system implemented by DINAPAM is highlighted, which includes the following lines of action:

- National Program of Homecare Caregivers

- National Program for the Promotion of Quality of Life for people with Cognitive Impairment, Alzheimer's and other Dementias.

-National Program for the Promotion of Personal Autonomy and Universal Accessibility for Older Adults:

Currently, the DINAPAM, in coordination with the University Institute of the Italian Hospital and the professional team of the Palliative Care Service has developed a new line for the training of home caregivers for elderly people with a specialty in palliative care.

The National Palliative Care Program has among its functions: a) the strengthening of the palliative care referral group in the country to be able to generate working groups by provinces and regions; b) the realization of specific referral and counter-referral protocols, to speed up the continuity of patient care, between the first level of care and specialized or support teams; c) the development of actions to favor the accessibility and availability of opioids for pain relief, guaranteeing traceability in accordance with the regulations in force and the respective auditing authorities; d) training for professionals in the prescription and use of opioids; e) conducting ongoing training activities in palliative care for doctors, nurses, psychologists and other members of the health team; the implementation of quality standards for palliative care; f) the generation of communication and dissemination materials in different media (graphics and audiovisual), aimed at raising awareness about the rights of the person with cancer to receive palliative care and help to install the integral approach that they promote.

In relation to long-term care, DINAPAM has 8 long-stay residences in which care is provided from a gerontological training focused on the person, considering their wishes and needs.

The National Institute of Social Services for Retired Persons and Pensioners (INSSJP-PAMI) holds sensitization seminars on the topic for primary care doctors and workers of the Institute regarding palliative care. As for rehabilitation services, they are available in INSSJP-PAMI coverage.

Social works such as the INSSJP-PAMI provide accommodation services and specialized long-stay care through recreational and therapeutic activities for maintenance, recovery and rehabilitation of skills, aimed at people with high vulnerability.

5. What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

Among the best practices, we can mention the adoption of the Regulation of Long-term Residences approved in 2015 (Res.612 / 15); the days of training in long-term care and the preparation of training material for the implementation of a new training line.

Among the challenges, the weak institutional articulation between the different organisms related to the theme and the absence of an integral law of long-term and palliative care stand out. On the other hand, each province has autonomy to define its own standards and some of them have not incorporated palliative care services. Thus, only 10 of the 24 provinces have provincial legislation on this care.

**Equality and non-discrimination**

6. Which are the measures taken to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situation?

In Argentina, not all hospitals have palliative care, but depends on the place of residence, whether the service is free or accessible and the requirements established in the institutions for access. The Mandatory Medical Plan (PMO) defines 100% coverage according to the general framework, so that insurance agents are obliged to provide the benefits mentioned in Annexes II and III of Resolution 201/2002 of the Ministry of Health of the Nation.

Regarding the accessibility of palliative care services, although there is some development of these, they do not have a generalized inclusion nor are they systematically integrated into the national health programs of the country, beyond pathology or age group. Although the coverage of Palliative Care services is mandatory, the main social security systems do not ensure this coverage, or in the case of covering them, due to the absence of a regulatory framework that controls it, non-specialized benefits are offered, but they are of low quality.

**Participation**

7. Does the design and implementation or normative and political framework related to long term and palliative care include an effective and meaningful participation of older persons?

The DINAPAM is in charge of the functioning of the Federal Council for Older Person, a space that brings together and articulates the implementation of all policies aimed at the elderly. These are two annual instances of joint work, among all the sectors committed to gerontological issues, which has a majority participation of the organizations of older persons belonging to all the provinces and regions of the country. In this space, older people express their needs and demands that are reflected in the policies implemented by DINAPAM.

On the other hand, in long-term residences dependent on the DINAPAM there are assembly spaces for the elderly in which they can express their claims, concerns and wishes to the institution and in terms of coexistence.

**Accountability**

8. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for their right to long-term and palliative care?

The Superintendence of Health Services is the entity for regulation and control of the actors of the sector, in order to ensure compliance with the policies of the area for the promotion, preservation and recovery of the health of the population and the effective realization of the right to enjoy the health benefits established in the current legislation.

The agency provides a free telephone, care centers and an online consultation where you can make inquiries, suggestions, complaints.

Exhausted this instance, the person can appeal to the ombudsman as an independent body established within the scope of the Congress of the Nation, who acts in the defense and protection of human rights, guarantees and interests protected in this Constitution and laws.

Likewise, people can appeal to competent judicial authorities when specific rights of older persons were violated. The Legal protection action is one of the tools that people have as established in Article 43 of the National Constitution "Any person can bring expeditious and fast action of protection, provided that there is no other suitable judicial means, against any act or omission of public authorities or individuals, which currently or imminently injures, restricts, alters or threatens, with arbitrariness or manifest illegality, rights and guarantees recognized by this Constitution, a treaty or a law. In the case, the judge may declare the unconstitutionality of the rule on which the act or omission is based".