GUIDING QUESTIONS AND ANSWERS FOR THE NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED WORKING GROUP ON AGEING:

Autonomy and Independence of End of Life Care & Decision

## National Legal Framework: The Legal Provisions in South Korea to Recognize the Right to Autonomy in End of Life Care and Decision?

## 1. Constitutional level

* Constitution of the Republic of Korea

->Article 10 All citizens shall be assured of human worth and dignity and have the right to pursuit of happiness.

**2. Legislative level**

* Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life [Enforcement Date 27. Mar, 2018.] [Act No.15542, 27. Mar, 2018., Partial Amendment]
* Act on the Improvement of Mental Health and the Support for Welfare Services for Mental Patients [Enforcement Date 16. Jul, 2017.] [Act No.164261, 29. May, 2016., Whole Amendment]
* Welfare of Older Persons Act [Enforcement Date 15. Jan, 2019.] [Act No.16243, 15. Jan, 2019., Partial Amendment]
* Act on the Prohibition of Discrimination Against Persons with Disabilities, Remedy against Infringement of their Rights, etc. [Enforcement Date 20. June, 2018.] [Act No.15272, 19. Dec, 2017., Partial Amendment]

**Normative Elements: Normative Elements of the Rights to Autonomy to Provide References and Standards**

* The right to be assured of human worth and dignity in end of life
* The right to receive appropriate counseling and guidance to make end of life care and decision
* The right to assure the best interest of older persons by respecting in end of life
* The right to appoint a trusted person to support/help the older persons in decision-making

**1.Universal Declaration of Human Rights**

->Article 6 Everyone has the right to recognition everywhere as a person before the law.

**2.Core International Human Rights Treaties**

2.1. International Covenant on Civil and Political Rights (ICCPR)

->Article 12,1. Everyone lawfully within the territory of a State shall, within that -territory, have the right to liberty of movement and freedom to choose his residence.

**->Article 19,** 1. Everyone shall have the right to hold opinions without interference.

2.2. Convention on the Rights of Persons with Disabilities

->Article 3 General principles (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;

**3. UN Report and Regional Conference**

3.1. Madrid International Plan of Action on Ageing

->Issue 2: Universal and equal access to health-care services -70, 74 Action (d)

3.2. United Nations Principles for older persons

->Care: 14,

-> Dignity: 18.

3.3. Inter-American Convention on Protecting the Human Rights of Older

-> Article 7 Right to independence and autonomy

->Article 11 Right to give free and informed consent on health matters

3.4. African Charter on Human and Peoples’ Rights

->Article 20: Right to Self-Determination

## Implementation: Best Practices and Main Challenges to Implement the Right to Autonomy and Independence.

## 1. Best practices

## Adopt the measures regarding older person’s end of life care decision with the national hospice care plan

## Adopt the measures that assure making advanced written statement for life-sustaining treatment to the person aged at least 19 with national registry system

## Adopt the measures that consult and guidance to older persons

## Adopt the measures that assure best interests of older persons with mentally and physically disabled

## 2. Main challenges

* Prohibited choices and options for older persons to make advance written statement for life-sustaining treatments (currently designated 52 medical institutions for superior hospitals, general hospitals, hospitals; 19 community NGOs, and 197 agencies for headquarters and branches of the National Health Insurance Services). [[1]](#footnote-1)
* Prohibited choices and options for older persons to make advanced written statement in the intermediate care hospitals (currently designated 11 out of 1529 intermediate care hospitals).
* Prohibited choices and options for older persons to implement of the right to POLST (Physical Orders for Life-Sustaining Treatment) (currently designated 173 medical institutions with bio-ethical committee to implement POLST).[[2]](#footnote-2)
* Strong inter-generational solidarity between older persons and adult children.

**Equality and Non-Discrimination: Older Persons, not Enjoyment to the Rights to Autonomy and Independence in the Vulnerable Situations**

with prohibition of the right to designate trusted person in written advance statement,

with prohibition of the right to execute the decision for life sustaining treatment,

Older persons are placing in vulnerable situations with absenting legal family members, hospitalizing in a medical condition that prevents them from expressing their intention, living in rural areas not in services, residing in where intermediate care hospital not in service, diagnosing with non-designated disease for hospice and palliative care, being with multiple condition by mental illness and disability, being with LGBT, and placing in prison.

## Accountability: Judicial and non-Judicial Mechanisms to Redress the Rights to Autonomy

1. **Judicial Mechanisms**

* Legislation for amendment to meet all the measures the right to autonomy and independence for older persons

1. **Non-Judicial Mechanisms**

* Build up new death culture that encourages “death talk”, “death discussion”, and “decision making for life-sustaining treatment” within family, community, and society.
* Empower older persons to aware their right to autonomy and independence in end of life care and decisions (83.1% of older persons agreed with death with dignity[[3]](#footnote-3)).
* Promote the right to education for “death”, “preparation for death”, and “death culture” from life-course perspective.
* Exercise civic movements to engage older persons right to autonomy and independence from the level of national, regional, and community.

1. https://www.lst.go.kr/medi/composableorgan.do [↑](#footnote-ref-1)
2. https://lst.go.kr/plan/composableorgan.do [↑](#footnote-ref-2)
3. https://www.humanrights.go.kr/ezpdf/customLayout.jsp?encdata=0D7B46D1D35E32531C97F3A723AB28689C3721EE62B784ED42C56510A003811E617EAD152899E52852CB5F486516C2B1F17F9E59C48C68DA6FE55F8A54C867401FB1201771C712189362BE6DEE07078DC71C40E7E4D7377B6C4A9CCE2C8B0185F3004098C91EF331FB177297B7DA8C7C4FFE9F300987D2994F43628C52A8F26C74484CB71D421A8F5AA4D4F47E70950144575271AD0887B8BD3F095182F210DB5B00F5FD41B0997C [↑](#footnote-ref-3)