



**Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on
Ageing: Long-term 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?

Family and friends—known as family caregivers—provide the vast majority of unpaid long-term care for older persons living in the community in the U.S. Two out of every three older people with self-care needs get all their care from their family members.

Long-term care—also known as long-term services and supports (LTSS)—is provided throughout state and federal policy frameworks. Medicaid, a federal-state program, is the principal public source of paid long-term care coverage. Public funding for long-term care is also provided by state home and community-based policies and programs, and the federal Older Americans Act. According to the [AARP LTSS State Scorecard](#), LTSS consist of a broad range of day-to-day help needed by people with long-term conditions, disabilities, or frailty. This can include personal care (bathing, dressing, toileting); complex care (medications, wound care); help with housekeeping, transportation, paying bills, and meals; and other ongoing social services. LTSS may be provided in the home, in assisted living and other supportive housing settings, in nursing facilities, and in integrated settings such as those that provide both health care and supportive services. LTSS also include supportive services provided to family members and other unpaid caregivers.

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

Affordability and access to LTSS are the biggest challenges. The cost of a nursing home is more than \$90,000 per year, and the cost of home care is more than \$30,000 a year for a home health aide for 30 hours a week at \$20 per hour. This care is not affordable for most middle-income families. Although the demand for LTSS is rising, relatively few adults have private long-term care insurance. Also, individuals and their families rarely plan for LTSS.

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 non-discriminatory basis?

We need financing that makes services more affordable to individuals and society—with shared responsibility among the government and private sectors and individuals. We also need a strong safety net—Medicaid—that covers a broad range of home and community-based services regardless of where a Medicaid beneficiary lives, his/her disability, or his/her age.

- High quality of services provided?

We need national measures or evidence-based outcomes because most people with self-care needs live at home or in the community. Yet, we know little about their quality of care or quality of life.



Real Possibilities

- Progressive elimination of all restrictive practices (such as detention, seclusion, chemical and physical restraint) in long-term care?

We need better enforcement of quality in nursing homes, with particular attention to ending inappropriate use of anti-psychotic medications, which should never be administered in order to sedate nursing home residents with dementia. Although there have been recent improvements, more than one out of six long-stay nursing home residents without a psychiatric diagnosis are sedated with antipsychotic medications. Medical professionals should be held accountable for this inappropriate prescribing.

- Sustainable financing of long-term care and support services?

We do not have sustainable financing of LTSS in the United States. The cost of LTSS over time remains much higher than what middle-income families can afford, and most adults do not have private long-term care insurance.

- Redress and remedy in case of abuse and violations?

Adult Protective Services help older people who are victims of abuse or neglect. However, these services are woefully underfunded and over-tasked.

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?

The U. S. Supreme Court ruled in the Olmstead case that the "integration mandate" of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." Although many state Medicaid programs are working to serve more people in home and communities rather than institutions such as nursing homes, the progress is very uneven. For example, while 69 percent of Medicaid LTSS spending goes to home and community-based services in Minnesota, it is only 14 percent in Alabama with the vast majority going to institutional care for seniors and adults with physical disabilities.

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

Yes, there are many promising practices. Some of them include:

- **Providing Person- and Family-Centered Care**, with an interactive process directed by individuals and family members to support decision making about LTSS. The care plan accounts for a person's and family's strengths, preferences, needs, and values.
- **Supporting Family Caregivers**, since they provide the lion's share of LTSS, by having:
 - Paid family leave and sick days since many family caregivers cannot afford to miss a paycheck and do not have paid sick days
 - Family caregiver assessments for their own needs because many caregivers endure physical and emotional stress



Real Possibilities

- Instruction for family caregivers to better enable them to provide increasingly complex medical/nursing tasks, especially upon discharge from a hospital
- Respite care and other supportive services to give caregivers a break
- **Reducing reliance on nursing homes** by:
 - Diverting people from nursing home care either before admission or shortly thereafter, so they can live at home or in a place that feels like home
 - Creating or expanding nursing home transition programs to move people out of nursing homes if they have a desire to do so
- **Preventing unnecessary hospitalizations** by:
 - Reducing hospital readmissions among high-risk people by averting hospitalizations of people in nursing homes and in home health, especially for those with dementia or at the end of life
 - Providing more home- and facility-based palliative care to give options beyond overly aggressive treatment at the end of life