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

Federal and state laws provide a wide range of important protections, so older adults can live a life of autonomy and independence, if possible. These protections include the rights to seek and maintain employment, to purchase products and services at fair and reasonable prices, and to obtain health care. The Age Discrimination Act prohibits discrimination on the basis of age in federally funded programs. The Americans with Disabilities Act protects people of all ages who have physical or mental disabilities. Despite these laws, enforcement can be problematic.

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?

Other essential rights include:

- Freedom from exploitation and abuse
- Protections against discrimination
- Safeguarding rights
- Choice (to make personal and financial decisions and to carry out his/her wishes and preferences in the event of future incapacity)
- Enforcement of rights
- Redress and support for victims

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?

Neglect, violence, and abuse. A common form of elder abuse is financial exploitation. A MetLife study estimates that the annual financial loss by older victims is at least $2.9 billion.

Social isolation. Socially isolated older adults are at greater risk for poor health and death than their well-connected counterparts. A new AARP study—the first to examine whether social isolation also affects health care spending among older adults—finds that a lack of social contacts among older adults is associated with an estimated $6.7 billion in additional Medicare spending annually.

Living in Home and Community-Based Settings. Most people want to live in their own homes and communities—or at least a place that feels like home—rather than institutions such as nursing homes. However, the majority of Medicaid long-term services and supports (LTSS) spending for older people and adults with physical disabilities goes to nursing homes. The AARP LTSS State Scorecard found that only 10 states spent more on home and community-based services than on nursing home care.
4) What steps have been taken to ensure older persons’ enjoyment of their right to autonomy and independence?

Most states are incrementally funding more home and community-based services with public funds. However, this funding varies widely, with most states needing to pick up the pace of change.

All 50 states have laws addressing elder abuse, and they have adult protective services to provide safeguards for adults who cannot protect themselves. However, adult protective services are woefully underfunded and overtasked.

The Elder Justice Act was enacted and is the most comprehensive federal legislation to combat elder abuse, neglect, and exploitation. However, adequate funding is of great concern.

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

Alternative Dispute Resolution (ADR). Contracts for a broad range of products and services often impose various forms of ADR—such as mediation and arbitration—to resolve conflicts. Voluntary nonbinding forms of ADR should be available to resolve disputes such as employment, health care, and purchases of goods and services. However, binding mandatory arbitration should not be imposed in these instances.

Legal Services. Because older adults have unique health, income, and social needs, they should have access to competent legal assistance. The Older Americans Act provides VERY limited funding for such services. The demand for these services has far outpaced the funding.

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

It should be a shared responsibility of government, the private sector, and the public -- and even self-and family-responsibility -- to respect and protect these rights. In fact, it is often the family caregivers who make living at home and in the community possible for many older adults with self-care needs because family caregivers provide the lion’s share of home and community-based services.