Guiding Questions for the focus areas of the IX Session of the Open-ended Working Group on Ageing: <u>Autonomy and independence</u>

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

The preamble to the San José Charter on the Rights of Older Persons in Latin America and the Caribbean mentions respect for autonomy and independence in decision-making as a fundamental right. Within this Charter, the two concepts are also mentioned in relation to the right to free and informed consent prior to any medical intervention, as well as in relation to care services, the improvement of living conditions and environment, and guaranteeing accessibility for older persons by eliminating architectural barriers.

The independence and autonomy of older persons have a prominent place in the **Inter-American Convention on Protecting the Human Rights of Older Persons**, being identified both as general principles (article 3) and as standalone rights (article 7). They also receive special mention in relation to the rights of older persons receiving long-term care (article 12) and the right of older persons to recreation, physical activity, leisure and sports as a means to promote their independence and autonomy (article 22).

Article 7 establishes that the States parties shall adopt programmes, policies, or actions to facilitate and promote full enjoyment of the right of older persons to make decisions, to determine their life plans and to lead an autonomous and independent life.

Autonomy and independence are specifically linked to three aspects of the lives of older persons:

- (i) Decision-making and action;
- (ii) The opportunity to choose one's place of residence and where and with whom to live, rather than being obliged to live in a particular living arrangement, and
- (iii) Progressive access to a range of in-home, residential, and other community-support services, including the personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community.

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?

Autonomy also involves the recognition of older persons before the law, encompassing their freedom and legal capacity to make decisions. The concepts of independence and autonomy demand that any individual's decision is legally respected. Denial or restriction of older person's legal capacity threatens their autonomy, with negative impact on the ability to exercise the right to make decisions on civil, commercial, administrative, judicial, health-related or other issues that may have an impact on their well-being. This leads us to the necessary interrelation between article 7 and article 30 of the Inter-American Convention on Protecting the Human Rights of Older Persons. The latter reaffirms the right of older persons to recognition before the law and establishes that States must ensure that all measures concerning the exercise of legal capacity will provide for appropriate and effective safeguards. Given the diversity of older persons and their needs, the nature and intensity of the support shall differ from case to case.

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?

The following list serves as a guide to the essential step that States can take in order to guarantee full respect for the autonomy and independence of older persons:

- (i) Examine the laws that regulate guardianship and trusteeship, and formulate laws and policies that will replace substitute decision-making regimes with supported decision-making, so as to respect the autonomy, will and preferences of the individual
- (ii) Replace substitute decision-making regimes with supported decision-making alternatives. The old regimes must be fully replaced; it will not suffice to develop two systems in parallel
- (iii) Ensure that the need to receive support and reasonable adjustments in order to make decisions will never be used in legislation or in judicial or administrative proceedings to cast doubt over a person's legal capacity.
- (iv) Establish a supported decision-making regime and procedures, always giving primacy to a person's will and preferences and respecting human rights norms
- (v) Adopt regimes based on supported decision-making. Although these may take various forms, they should all be based on certain key provisions:
 - All forms of support in the exercise of legal capacity must be based on the will and preference of the individual, not on what is perceived as being in his or her objective best interests.
 - Support in decision-making must not be used as a justification for limiting other fundamental rights (such as the right to vote, the right to marry or establish a civil partnership, the right to give consent to medical treatment and the right to liberty).
 - The person must have the right to refuse support and terminate or change the support relationship at any time.
 - Safeguards must be set up for all processes relating to legal capacity and support in exercising legal capacity. The goal of safeguards is to ensure that the person's will and preferences are respected.