

## **Open-ended Working Group on Ageing**

Ninth working session

### **Analysis and overview of guiding questions on autonomy and independence received from Member States, “A” Status National Human Rights Institutions and accredited non-governmental organizations**

#### **Background**

The Open-ended Working Group on Ageing, established by the General Assembly in its resolution 65/182 with the purpose of strengthening the protection of the human rights of older persons, will hold its ninth session at United Nations Headquarters from 23 to 26 July 2018. The substantive discussions will focus on two focus areas: autonomy and independence, and long term and palliative care. To that end, the Bureau called for substantive inputs from Member States, national human rights institutions, non-governmental organizations and United Nations system agencies and bodies, following questionnaires prepared by the Secretariat on the two focus areas.

During the ninth session, the Open-ended Working Group on Ageing will consider and discuss the contributions received, based on the summary documents prepared by the Secretariat. The present document contains the analytical summary of contributions on the focus area: autonomy and independence, following the six guiding questions of the questionnaire.

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

Respondents identified the right to autonomy and independence as a basic human right of older persons. Nonetheless, few submissions provided specific definitions of the right. Some respondents pointed to the fact that explicit standards on autonomy and independence of older persons in international human rights law were insufficient. Whereas a number of instruments recognized the right, those standards varied and were inconsistent across regions.

A joint submission by several non-governmental organizations defined autonomy as the ability to make choices and decisions, including with support if necessary, according to one's conscience, values, will and preferences. In turn, independence was the ability to perform actions of daily living and participate in society in accordance with one's will, values and preferences. Correspondingly, a submission by a non-governmental organization defined the right to autonomy and independence of older persons as "making their own decisions without interference from others and being free to enjoy their rights". This encompassed being able to participate in family and cultural life, acting on their own ideas, doing things for themselves, solving their own problems and achieving their goals are all central to independence.

One national human rights institution proposed a definition of the right to autonomy and independence paramount for living with dignity during the ageing process. It comprised the right to take all relevant decisions about one's life with autonomy and freedom, including inter alia the decision where to live, free income and assets management, and choice of healthcare received.

### ***Normative references***

In the majority of cases, responses described legal references to the right, instead of concrete definitions. Many mentions to the right to autonomy and independence of older persons were embedded in constitutional provisions. Most examples addressed the right indirectly, as part of the duty to “protect” this population group, or to recognize its participation in society and its contribution to development.

For instance, the constitution of Kenya stated that the State should take measures to ensure the rights of older persons to fully participating in the affairs of society, to pursuing their personal development, to living in dignity and respect and be free from abuse, and to receiving reasonable care and assistance from their family and the State (article 57). The constitution of Portugal enshrined the right to economic security, housing and family and community living conditions that respected the personal autonomy and prevented isolation or social marginalization of older persons (article 72). Similarly, the Charter of Fundamental Rights of the European Union recognized the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life (article 25).

Submissions evidenced steady legislative progress. Several countries passed or are in the process of drafting specific laws on the rights of older persons, which contemplated directly or indirectly the right to autonomy and independence at their core. Nevertheless, respondents noted that many laws and policies seemed to maintain an assistance or needs-based approach rather than a rights-based approach. References such as the “special protection” of a “vulnerable” group evidenced this. In some other cases, including the 2005 Law on “adapting society to ageing” of France, the focus of legislation was on the environmental and social factors rather than in the needs of individuals. Likewise, the 2002 Law on the Rights of Older Persons of Mexico defined the principle of autonomy and self-realization covering all actions aimed at strengthening the independence, decision-making capacity and personal and community development of older persons.

In addition, many legal provisions contemplated the right of autonomy and independence of older persons within mental health legislation or the framework for the rights of persons with disabilities. In particular, the concepts of the Convention on the Rights of Persons with Disabilities spearheaded a new paradigm regarding juridical capacity and support mechanisms that promoted a rights-based approach that benefited older persons in the enjoyment of their rights. Still, while stressing the importance of these legal provisions, some respondents warned on the conceptual need not to automatically associate older age with disability.

The right of autonomy and independence of older persons was also central to the numerous national action plans or policies on the rights of older persons reported. These policies included the establishment of national care systems and promotion of support mechanisms, as described in the responses to question four. For instance, the 2014 Lesotho Policy for Older Persons, adopted a rights-based approach, and included independence as one of its guiding principles. Similarly, the non-binding Charter of Rights for People in Need of Long-term Care and Assistance of Germany recognized the right of older persons to live a life as self-determined and independent as possible.

Some respondents highlighted the need to follow the model of the Inter-American convention on protecting the human rights of older persons, which contained independence and autonomy of older persons as a general principle (article 3), and as a detailed stand-alone right with encompassing State obligations (article 7). The Convention recognized the right of older persons to make decisions, to determine their life plans, to lead an autonomous and independent life in keeping with their traditions and beliefs on an equal basis, and to be afforded access to mechanisms enabling them to exercise their rights. State obligations included facilitating access to a range of in-home, residential, and other community-support services, including personal assistance necessary to support living and inclusion in the community and to prevent their 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?**

From most of the responses received, autonomy and independence were underlying principles that governed every human right of older persons. In that sense, responses enumerated numerous concepts in replying this guiding question.

A quantitative analysis of the inputs received revealed that health was, by far, the right mostly emphasized in answering this guiding question. Mentions referred to not only the rights of older persons to equal access to healthcare and to physical, psychological and sexual integrity, but also to receive comprehensive information and full and informed consent, appropriate health and hygiene standards, and active ageing. Responses to question four provided several examples of policies that promote family and long-term as a central element of this right.

Several respondents mentioned the rights to equality before the law and legal capacity, as key aspects of autonomy and independence, including access to systems for supported decision-making. Furthermore, numerous submissions stressed the need to ensure the rights to participation in the community and in public life, access to social security and social protection, housing, education, access to justice and effective redress, equality and non-discrimination and freedom from violence, abuse, negligence, in order to guarantee the enjoyment of the right to autonomy and independence by older persons.

In a lesser extent, submissions enumerated other rights, including employment, freedom of movement and accessibility, access to transportation, consumer protection, culture, recreation, security and safety, respect, dignity, privacy, food and nutrition, property and livelihood, the right to age in place, freedom of opinion and association, freedom from exploitation and persecution, among others.

**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?**

Inputs received stressed the obligation of States to eliminate structural and institutional discrimination, including prejudices, ageism and the stereotypical image of old age associated with disability and unproductivity, which was the main cause for exclusion of older persons and denial of their human rights. States should have due regard to the differential impact of their decisions, in particular age-based policies, on older persons.

### ***Issues and challenges raised***

Most of the key issues and challenges identified corresponded to one or more of the human rights mentioned in the answers to question two. Consequently, many replies pointed challenges to access to health services and other health issues, including the right to previous and informed consent and access to palliative care. High rates of abuse, violence, neglect and abandonment were also among the most frequently raised concerns.

Other recurrent answers highlighted insufficient income, poverty or access to social security and pensions, including the disproportionate burden caused by the HIV/AIDS pandemic upon older persons caring for orphans. In addition, respondents pointed the lack of support networks and alternative care, sufficient funding for care programs, as well as the need to promote family living and aging in place, among other alternatives to institutionalization. On the contrary, the rights to participation and the lack of a legal framework for supporting the exercise of the right to legal capacity had very few mentions; therefore, the relevance given conceptually to some of these basic human rights in question two did not necessarily correspond to the most pressing issues and challenges identified in question three.

Respondents warned about increased inequalities affecting older women with regard to access to healthcare, employment, income security, and women living in rural or isolated areas. Similarly, there were several regional and rural disparities affecting minorities in some countries, and persons over 80 faced a disproportionately higher risk of exclusion and abandonment.

Other issues and challenges identified included barriers to access to justice; the need for proper infrastructure, transportation and accessibility; higher disability rates in older population; the need for training of health staff and public officials; insufficient access to housing, land, property and inheritance rights; and lack of participation of older persons in public life and in their communities. In addition, respondents condemned violations of older persons' intimacy, hygiene and privacy in residential homes; lack of access to financial services; unequal access to employment and education; and inadequate access to information and communication technologies, among others.

### ***Availability of studies and data***

Reports on the existence of national studies and data were diverse. Although many pointed the lack of disaggregated useful data or failed to deliver information on its availability, some others provided illustrations of successful practices regarding national surveys and specialized studies by states, national human rights institutions and non-state actors.

Examples included national surveys on the quality of life of older persons and in long-term homes in Argentina, a national survey on the “use of time” to assess functional dependency of older persons in Colombia, and social reports and studies on the elderly in Dominican Republic, Germany, India, Kenya, Mauritius, Morocco, State of Palestine (non-member observer state), and Viet Nam. In the European Union, an Active Ageing Index developed by the European Commission and the United Nations Economic Commission for Europe aimed at enhancing availability of statistical on this subject.

#### **4) What steps have been taken to ensure older persons' enjoyment of their right to autonomy and independence?**

A wide array of measures and strategies were being implemented by all stakeholders. State and non-state actors called for the adoption of international standards, including some of them advocating to create or become part in international binding instruments. In addition, specific laws on the rights of older persons had been drafted. Whereas some maintained a needs-based approach, addressing protection measures with a vulnerability perspective; the majority of countries reported reforms aimed at strengthening legal protection and guardianship systems, in order to adapt them to a rights-based paradigm.

The Inter-American convention of protecting the human rights of older persons was the standard followed by some countries; since it provided for appropriate and effective safeguards to prevent abuse in the exercise of legal capacity by older persons (article 30). In Argentina, the new Civil and Commercial Code recognized right to support systems for decision making. Legal representation for decision making was reserved only for exceptional cases. Additional legal mechanisms were introduced, such as enduring power of attorney in Germany. In other countries, older persons found legal mechanisms to exercise juridical capacity that were established in legislation inspired in international standards set by the Convention on the Rights of Persons with Disabilities (article 12). Such is the case of the 2016 Law on personal autonomy of persons with disabilities of Costa Rica.

Submissions described the establishment or strengthening of domestic care programs and family support under the ageing in place principle, with focus in deinstitutionalization. Measures included the legal redefinition of long-term care and recognition the legal status of family caregiver. France, for example, recently established the legal figure of the right to respite care. Some countries reported progress in the establishment of national care systems, including volunteer services and community-level support networks. The Dominican Republic, for example, described a care system with a preventive, coordinated and integrated model, including domiciliary visits, services to promote personal autonomy and prevention of dependency, attention and care of situations of dependency, and professionalization of care services.

The broad diversity of policies and measures reported included:

- Multidisciplinary consultation services at local government level and emergency hotlines.
- Creation of multiple publicly funded self-help groups, organizations and contact points.
- Extension of pension system coverage and higher incomes.
- Inspections in social care centers.
- Economic and fiscal incentives, such as senior citizen card for discounts.
- Pensions and health insurance benefits for older persons living in poverty and older persons with disabilities.
- Preferences for older persons in some services.
- Policies for accessing land, housing loans, grants and mortgages.
- Policies for creating age-friendly living environments, including fall prevention strategies.

- Programs for the promotion of autonomy, domestic care, good treatment, and equality.
- Establishment of daycare centers.
- Extension of working years.
- Legal prohibition of prison for individuals over 70.
- Universalization of palliative care in health systems.
- Increased transparency and information regarding senior housing.
- Adoption of codes of medical ethics to oblige medical doctors to respect the will of older patients.

Numerous submissions additionally described awareness creation and capacity-building efforts at all levels, including campaigns for the promotion of positive concept of life long development, trainings for health staff, judges and other public officials, education for families, and sensitizing campaigns aimed at older persons. Awareness raising programs aimed at informing older persons of their rights, promoting self-respect, confidence, self-improvement, and encouraging their participation in public affairs. For example, in Colombia, the “life centers for older persons” program worked at local levels, promoting functional independence and personal autonomy through active and healthy aging. Likewise, the national action plan for positive ageing of the Czech Republic was entering its fourth cycle, promoting autonomy, active ageing and combating stereotypes and discrimination against older persons. In Malta, the national strategic policy for active ageing for the period 2013-2020 included 75 policy recommendations.

Institutional changes to implement these measures included the establishment of elderly service offices for public attention and information, the creation of specialized directorates within State ministries, assigning specific competences for monitoring care services and other issues or importance to older persons to ombudsperson offices or national human rights institution, and establishing national preventive mechanisms in charge of visiting places of detention, nursing homes, and psychiatric hospitals in order to prevent violence and abuse against older persons, among others.

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

Submissions describing measures needed or in place to remedy the denial of autonomy and independence of older persons varied in form and substance. Wide-ranging public policy measures to enable redress implied making available more information and awareness about the rights of older persons for themselves and society as a whole, especially families and relatives. A rights-based approach needed more involvement of non-governmental organizations and other relevant actors, such as local governments and the private sector. It should be consolidated through capacity building for public officials and special trainings at all levels, including service providers, medical staff and families.

The promotion of the new paradigm would strengthen the protection of the human rights of older persons by allowing the enforcement of existing laws in general courts, administrative bodies and national human rights institutions. Cultural, religious and social values, as well as State programs to promote intergenerational solidarity and increase awareness among the younger generation also helped to avoid the denial of autonomy and independence and

facilitate redress. In that line, some respondents called for international human rights standards to guarantee the right to freedom of personal autonomy and legal capacity of older persons, to make decisions, to determine their life plans and to lead autonomous and independent lives in line with their will and preferences and on an equal basis with others. This included the right to have those decisions respected.

Legal reforms aimed at guaranteeing and safeguarding the right to legal capacity appeared as central to the right to autonomy and independence. Most reforms reported foresaw the establishment of support systems, including enduring powers of attorney, as alternatives to legal guardianship, which should be a last resort. One respondent defined support as “any measure of legal or non-legal nature that facilitates the decision making by the person in need of such support with regards to its own person, the administration of its property and conducting legal acts in general.” Furthermore, new appeal mechanisms and compulsory reviews at the administrative and judicial levels existed for cases of legal guardianships and long-term care. Respondents warned that confidentiality and secrecy had to be guaranteed in those proceedings. Some of the rules for redress were specifically aimed at older persons, although many were part of laws with focus on mental health or the rights of persons with disability.

The States Parties to the Inter-American convention on protecting the human rights of older persons incorporated its article 31, which strengthened the right of equal access to justice of older persons, including through the provision of procedural accommodations in all legal and administrative proceedings at any stage and the establishment of alternative dispute settlement mechanisms. The Convention also obliged States Parties to ensure due diligence and preferential treatment for older persons in processing, settlement of, and enforcement of decisions in administrative and legal proceedings; and to make judicial action particularly expedited in instances where the health or life of the older person may be at risk.

Legal amendments also included widening the definition of family violence by including dishonestly misappropriating of property, which caused the victim to suffer distress. Some legislations established increased protection measures for violence situations, and established criminal provisions for denial of autonomy and independence. Other legal reforms included the establishment of the rights to petition, mediation, legal aid, and tortious liability of residential institutions. In addition, some countries made reasonable adjustments in judicial proceedings, such as giving priority or preference for older persons and providing judicial assistance.

Submissions additionally described a number of measures implemented at the policy level, such as increased monitoring of social and long-term care facilities, particularly regarding limitation or restraint of older persons. Some respondents highlighted the need for periodic phone-call and home-visit check-ins mechanisms, as well as emergency hotlines, and community-based services such as meals, hygiene, and health consultation. At the institutional level, reforms to strengthen redress included providing specific monitoring powers to human rights institutions, creation national or local advisory councils for older persons, establishing supervisory bodies with competences to receive complaints, perform inspections and settle disputes, and multidisciplinary aid for older persons, victims of violence, abuse or abandonment.

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

There was broad consensus among the submissions received on the fact that respecting, protecting and promoting the rights of older persons, including the right to autonomy and independence, is a common responsibility for the whole society. In some cases this was stated in national constitutions and legislation. Families played a central role in recognizing the skills, competences and abilities of their older members, propitiating an environment of respect, recognition and help, and helping to satisfy the basic needs of nutrition, health, physical, psychosocial, emotional and affective development of older persons.

Civil society and grassroots organizations played a leading role changing the stereotypical image of older persons, old age and ageing. They promoted a vision of active ageing and highlighted older persons' contribution to society and development, highlighting their knowledge, skills and abilities. Within their line of work, non-governmental organizations helped to detect pressing problems, guarded observance of the relevant legislation and promoted participation of older persons in public life. They informed the public about injustices and disseminated information, good practices and values.

At the community level, these organizations carried out programs to facilitate preferential treatment for older persons in certain circumstances, organized self-help and support groups, and established offices for advice and support of senior citizens. They offered psychological, social and legal support; and providing social services, including humanitarian aid during emergencies and natural disasters. Local pilot projects offered new approaches and promoted knowledge transfer between non-state and governmental stakeholders; while voluntary local actors alongside their networking partners contributed to ensuring participation and involvement in old age. In addition to their lobbying and advocacy roles, in some countries non-governmental organizations and representatives of older persons participated in multi-disciplinary and cross-sectoral national advisory bodies or councils for older persons and pensions committees, deliberating issues affecting older persons and having a voice in the policy-making process.

Local and state governments also had responsibilities identified. In some countries the law required local governments to assign resources to promote wellbeing of older persons and community engagement in line with the concept of ageing in place. They also had a mandate to strengthen collaboration with relevant organizations and to conduct public awareness activities. In Japan, for example, the Act on the Prevention of Elder Abuse assigned local governments the responsibility to make initial response in cases of threat to life or health of older persons; and gave them the authority to order reports, on-site inspections, make recommendations, orders measures regarding care services.

Respondents also highlighted the role of national human rights institutions in advocating and monitoring compliance with the right to autonomy and independence of older persons at all level, as well as serving as an avenue for redress. Furthermore, private companies also played a role in promoting the autonomy and independence of older persons, mainly by complying with national and international human rights standards. Respondents described measures such as reinserting older persons into the labor market, taking into account their expertise, and making reasonable adjustments to facilitate their inclusion in the workforce. Consumer rights of older persons should also be promoted and protected by the private sector. Private sector

actors should also support programs aimed at promoting active ageing and quality of life in old age as part of their social and development engaging.