MEMORANDUM

Date: September 12, 2018

To: Robert M. Carlson, President
    Jack Rives, Executive Director
    Holly O’Grady Cook, Director, Government Affairs
    Mark H. Alcott, ABA Representative to the United Nations

CC: Christina Heid, Director, Section on International Law
    Tanya Terrell, Director, Section on IR&R
    Michael Pates, Director, Center on Human Rights
    Katy Englehart, Office of the President
    Charlie Sabatino, Director, ABA Commission on Law and Aging

From: William B. T. Mock, ABA Liaison to the UN OEWGA
    Professor, The John Marshall Law School, Chicago

RE: Liaison Report on the Ninth Working Session, July 23-26, 2018,
    of the United Nations Open-Ended Working Group on Ageing (OEWGA)
    http://social.un.org/ageing-working-group

In August 2014, ABA President William Hubbard appointed me to serve as the ABA representative to the U.N. Open-Ended Working Group on Ageing which is charged with considering avenues to strengthen the protection of the human rights of older persons. I succeeded William L. Pope who served in that role since 2012. The appointment and participation of a liaison, supported by the Commission on Law and Aging, has been the primary implementation strategy for the resolution adopted by the House of Delegates in August, 2011, that states:

RESOLVED, That the American Bar Association urges the United States Department of State and the United Nations and its member states to support the ongoing processes at the United Nations and the Organization of American States to strengthen protection of the rights of older persons, including the efforts and consultations towards an international and regional human rights instrument on the rights of older persons.
In August of 2018, the House of Delegates adopted a related resolution that acknowledges the recently enacted Inter-American Convention adopted by the Organization of American States and expressly advocates for a similar U.N. convention:

RESOLVED, That the American Bar Association supports in principle the Inter-American Convention on Protecting the Human Rights of Older Persons and encourages the United Nations, operating through its Open-Ended Working Group on Ageing or similar process, to draft a convention on the rights of older persons, considering the Organization of American States Convention as an instructive precedent.

In my capacity as liaison, I have attended the annual meetings of the Working Group in 2015, 2016, 2017, and the most recent one, the 9th Session of the Working group, held July 23-26, 2018 at the United Nations in New York City. This memorandum summarizes the proceedings of that meeting, in which I was accompanied by Charlie Sabatino, Director of the Commission on Law and Aging.

Ambassador Martín García Moritán, the Permanent Representative of Argentina to the United Nations, chairs the Working Group. Alternates filled in at various times. The first day was comprised of housekeeping matters and then general discussion that allowed individual states and a few non-governmental organizations (NGOs) to make opening statements. The core of the meeting, starting on Day 2 was organized around two topics for which the Working Group asked for specific input from states, human rights organizations, and NGOs representing civil society. These focus areas were:

- Autonomy and Independence
- Long-Term Care and Palliative Care

For each of the topics, input had been invited prior to the meeting on several dimensions of the topics, including how these rights are defined in the respondent’s country or region; what are the key issues and challenges facing older persons regarding these rights; how are these rights implemented and redressed when violated; are there best practices; and what is the role of non-state actors in respecting and protecting these rights?

Day Two focused specifically on Autonomy and Independence and was structured around two panels of experts followed by interactive discussion. The agenda with panelists identified is attached. My statement as ABA liaison in that discussion is attached (Statement 1).

Day Three focused on Long-Term Care and Palliative Care, again organized around two panels of experts followed by interactive discussion as the agenda shows. My statement as ABA liaison in that discussion is attached (Statement 2).

Day Four focused on normative inputs that clarify the nature and extent of human rights as specifically applicable to older persons. Normative areas included not only autonomy, independence, long-term care, and palliative care, but also areas discussed in the previous meeting of the Working Group (age discrimination, and elder abuse). This discussion fell into a debate that has recurred in all the meetings of the Working Group, i.e., whether a new specialized
convention on the rights of older persons is needed, or whether existing human rights instruments are sufficient in their normative standards and all that is needed is stronger enforcement of existing international instruments (most notably the Madrid International Plan of Action on Ageing), and enhanced dissemination of best practices.

Notably, civil society and national human rights institutions expressed strong support for a convention on the rights of older persons, emphasizing the importance of elaborating both general principles and specific rights as applied to older persons. Among member states, several Latin American countries have been the strongest advocates of a new convention. The U.S., Canada, the European Union, China, and Japan have been most vocal against a new convention, although there are a few border-line members among those anti-convention constituencies. The European Union participated more concretely than in previous meetings in discussions defining particular normative rights and Canada on day four expressed “an open mind” on the need for a convention. My statement as ABA liaison supporting the drafting of a convention is attached (Statement 3).

The meeting closed with a brief summary from the chair and an expressed intent to structure a 2019 meeting around two more normative topics of inquiry and to progress further in defining substantive rights more fully in their application towards older persons.

Attachments:
Proposed Organization of Work (the Agenda)
Statements 1, 2, and 3 by Liaison William Mock
# Agenda

### Proposed Organization of Work

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<td>• Maria Scolfedo Cisternas Reyes, General Deputy of the UN Secretary-General on Disability and Accessibility</td>
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### Proposed Organization of Work

**Other Matters:**
- Selection of focus areas for the next working session of the Open-ended Working Group on Ageing

**Item 8:**
- Provisional agenda for the next working session of the Open-ended Working Group on Ageing

**Item 9:**
- Consideration of the draft provisional agenda

**Item 10:**
- Adoption of the draft report Closing
First Statement

By Professor William Mock, American Bar Association Liaison
to
the United Nations Open-Ended Working Group on Ageing

24 July 2018, afternoon session

*Perspectives on Autonomy, Independence, and Access to Justice*

Thank you, Madame Chair.

People have autonomy when they have the opportunity to make their own decisions about themselves, either alone or with assistance. People have independence when they are free and able to carry out their own autonomous decisions. In modern society, independence must be understood as occurring in the context of the full range of social resources, including financial, housing, health-care, community-based supportive services, technological assistance, and social connection and participation. Thus, autonomy and independence are inextricably bound with each other, just as they are both central to the human right of dignity. A right to self-directed decision-making means little unless the legal, economic, social, and physical environments support autonomous decision-making and independent action.

Access to justice is thus key to providing and maintaining autonomy and independence to all persons, including older persons. Please consider the following examples of this reality.

Retaining one’s independence requires legal support in planning for one’s later years, whether in estate planning or in making one’s health decisions and end-of-life choices known and legally binding. Legal expertise in preparing estate plans, powers of attorney, living wills, and property transfers is largely absent for poorer older persons. Currently, public legal services in the United States provide less than one-quarter of the estimated legal needs of the lowest income older persons.

Effective legal representation is also central to issues of guardianship and conservatorship. Within the United States, about 1.5 million adults are under guardianship or conservatorship, too often created without any real legal representation of the affected person. Often, including in cases involving guardianship or conservatorship of older persons, the affected person is not even present to protect their own autonomy and independence from being taken away. Furthermore, despite a declared national policy in favor of limited guardianships, plenary guardianship is too often the default norm.

For older persons needing long-term residential care, neglect and abuse are all too common. When that happens, access to courts and the remedies they offer is vital to protecting the older person’s remaining autonomy and independence. Unfortunately,
regulations allow nursing homes to require individuals needing their services to waive their rights of access to the courts, substituting mandatory arbitration as a condition of admission. Such arbitration is widely regarded as an inferior venue of protection for the rights of older persons.

Older persons have, as this Working Group has often discussed, a special combination of legal challenges, many of them (like abuse and exploitation) relating to autonomy and independence. Central to addressing these challenges and protecting these rights is the existence of a judicial system that facilitates legal action by older persons and the issues they face. Nevertheless, most prosecutors lack training in the legal issues of older persons and few court systems in the United States have divisions focused on these issues. Commonly, cases drag on for years, to the particular detriment of older persons of limited means and years.

Access to justice is central to the protection and enforcement of all human right. These include access to legal information, advice and representation, as well as access to judicial institutions to protect their rights. It is for this reason that the American Bar Association calls upon this Working Group to support access to justice as fundamental to the human rights of autonomy and independence.

Thank you.
Thank you, Madame Chair. I am Professor William Mock, here representing the American Bar Association at the Open-Ended Working Group.

Eighteen years ago this month, the American Bar Association adopted a Resolution calling upon all levels of government to amend their laws to remove unnecessary barriers to quality pain management. I quote:

the American Bar Association urges federal, state, and territorial governments to support fully the right of individuals suffering from pain to be informed of, choose, and receive effective pain and symptom evaluation, management, and ongoing monitoring as part of basic medical care, even if such pain and symptom management may result in analgesic tolerance, physical dependence, or as an unintended consequence shorten the individual’s life.

We stand by those words today.

Fundamental human rights address what it means to be a person with dignity and autonomy. Among these is the right to be free from unnecessary pain and suffering, whether from chronic illness or from the natural process of approaching death. In short, palliative care.

By themselves, fundamental rights are powerless except as broad principles. They need other, more instrumental human rights to give them practical effect, including rights of political participation, access to education and information, and access to justice. It is only with these more instrumental rights that it becomes possible to identify, remedy, prevent, and eliminate violations of our human rights. Thus, access to palliative care will remain merely a wonderful principle unless and until it is embodied in a legally-binding instrument that includes clear rights of access to justice.

In 2014, the WHO called for palliative care to be integrated as an essential element of the health care continuum. Yet palliative care remains fragmented, sporadic, largely local, and often limited to people with cancer and those who are dying. Today, most people living with serious chronic illnesses lack access to palliative care, including those living at home, those in assisted living facilities, and those in nursing homes. So long as
recognition and regulation of palliative care rights remain fragmented and aspirational, so will palliative care itself.

Access to essential medicines for pain relief is distorted by policies unrelated to human needs. For all of these, remedial steps must involve both the recognition of palliative care as a fundamental human right and empowering those suffering from severe pain to seek legal remedy for unnecessary pain.

As one example, regulation of access to opioid medicines is seriously limited by national policies relating to prevention of drug abuse. Without recognition of palliative care as a fundamental and enforceable human right, the needs of those with severe and medically unnecessary pain remain hostage to a never-ending War on Drugs.

Seriously deficient palliative care should be actionable as sub-standard care, medical malpractice, and even elder abuse. In 2001, a California court found medical providers liable for Mr. William Bergmann’s unnecessary suffering prior to death under that state’s elder abuse statute. Even outside of California, every person should have a legally-enforceable right of meaningful involvement in all aspects of their care, including assessment of need, planning for care, delivery of care, and post hoc review. All of this requires recourse to institutions of justice.

In sum, the lack of a rights-based foundation to palliative care contributes significantly to preventable suffering. It is time for a legally-binding international document that includes both palliative care and access to justice.

Thank you.
Third Statement
By Professor William Mock, American Bar Association Liaison to the United Nations Open-Ended Working Group on Ageing
26 July 2018, morning session

Perspectives on Need for a New Convention

Thank you, Madame Chair.

We appreciate the opportunity to speak, and wish to address the concerns raised by the distinguished delegate from the United States.

It is true that existing human rights documents can be read to include protection of older persons. However, it is also true that such documents can be read without reference to older persons. In fact, the Universal Declaration of Human Rights, perhaps the most important human rights document of the past century, does not even mention older persons or age as a protected category.

Later human rights instruments mention older persons in passing, but do not provide any focus on the special problems of aging, either along or in combination with other vulnerabilities.

Thus, to defend the rights of older persons under these instruments requires arguing from first principles, which any lawyer can tell you is orders of magnitude more difficult to do than arguing from specific rights and prohibitions. Similarly, it is far easier to overlook older persons when there is no specific instrument that addresses older persons and their issues.

A second argument has been raised – that it is inefficient to focus on developing a new instrument to protect the rights of older persons, and that we should instead work on greater enforcement of the general rights expressed in existing instruments.

This is a false choice. In a world where abuse, neglect, and societal abandonment of older persons is rampant, we are entirely failing to take into account the far greater inefficiencies of losing the contributions of older persons throughout societies. Traditionally, older persons have always been seen as national treasures. Will we now throw away those treasures because of a false either/or claim of inefficiency? Was it inefficient to protect the rights of women in CEDAW? Was it inefficient to protect the rights of the Disabled and the rights of Children?

There is no valid excuse left for not moving forward to a United Nations Convention on the Rights of Older Persons.

Thank you.