

# Watching the Watchdogs: Oversight of Nursing Home Regulators



Monday July 23, 2018 *Age and Youth in Action*

## At the Open Ended Working Group on Ageing

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**Summary prepared by Rachella Ferst and Jonathan Berger**

This year, at the 2018 Open Ended Working Group on Ageing at United Nations Headquarters, Gray Panthers [www.graypanthersnyc.org](http://www.graypanthersnyc.org) sponsored and organized an important panel discussion entitled “Who’s Watching the Watchdogs? Oversight of Nursing Home Regulators.” Five experts, with differing perspectives on how to achieve effective regulation, presented to an audience of more than 50 delegates attending the OEWGA. They include a representative of: the World Health Organization; Human Rights Watch; Long Term Care Community Coalition; Comptroller of the State of New York; and International Longevity Centre/ Canada - University of Ottawa.

We’ve identified key messages from our excellent panelists as well as providing a link to each person’s worthwhile presentations.

### **Why this is topic so important?**

Regulation of nursing homes is essential to ensure that the best care (medical and residential) is provided to the most vulnerable. But, who is watching the watchdogs? Independent, tenacious, knowledgeable auditors and advocates must protect the human rights of these nursing home residents. Yet, these residents retain the right to make decisions on their care and treatment. They are entitled to quality care as well as the highest standard possible of protection of rights and life. This is a global issue, not just one to be swept away. This is particularly true for regions of the world where effective long term care facilities for older persons, medically and emotionally infirm, are being developed. This session explores the need for effective oversight, examples of successful watchdogs, and challenges to ensure that the human rights of older persons in long term care facilities are adequately protected

Given the theme of this year’s Working Group on Ageing involves identifying the human rights issues needing protection for older persons in the context of long term care and palliative care, the concept described above has immediate and important applicability.

### **But, who is actually watching the watchdogs?**

It is essential that we effectively monitor the systems and institutions that seek to provide care for older persons -- but who really is watching the watchdogs? Even if regulators have the best of intentions, it is the responsibility of civil society, auditors, those who understand accountability to remain vigilant regarding enforcement of existing regulations as well as conduct robust advocacy for improvements in the approach and/or details of the regulatory scheme. The human rights of persons in institutions, particularly those in long term

care, is one of the things that is not sufficiently discussed and examined. Rights for persons in long term care facilities must be protected and clarified. It is critical that we give voice to those within these institutions. We should empower them and others to ensure that these systems do not endanger and exploit the very people that they are designed to help. Protecting their autonomy in decision making and in all aspects of their lives must be paramount. This is yet another example of institutional ageism, where the concerns of older persons are inadequately addressed and often ignored.

Perspectives ranged from domestic policy and programs combating abuse of older persons to more global concepts of implementing programs in the developing world. Moving toward a globally adopted convention to protect the human rights of older persons, the concerns of those in long term care facilities have unique human rights aspects which must be addressed.

#### Key messages:

- Regulation of nursing home is essential and requires the active participation and surveillance of Civil Society and government oversight entities, including legislators and auditors.
- There are an estimated 179,000 older people given antipsychotic drugs every week in the US. Many are being given these drugs against their independent freewill.
- Clear violations of human rights occur in nursing home and long term care facilities. For **example**, the often unnecessary administration of antipsychotic drugs to residents facing dementia.
- Advocacy groups, such as the Long Term Care Community Coalition, Human Rights Watch, and Gray Panthers, play a critical role that provide original insights and identify new approaches to - improving care, preserving autonomy, and protecting human rights.
- Chronic disease management will be at the forefront of healthcare for older adults in the future. Fundamentally important to persons in care facilities is that their right to care, autonomy and quality of life must be recognized and protected. A societal mindset must evolve so that the notion that lives and dignity of older persons-- even those with advanced chronic disease-- can continue to flourish, and be pleasurable.
- Current indicators used to monitor programs tend to focus on outcomes, facility compliance, and finances. They do not focus on life satisfaction of individuals.
- In the USA, there are a variety of statutes, agencies and regulatory systems overseeing all aspects of nursing homes, such as the Nursing Home Reform Law, the Center for Medicare and Medicaid Services, and each state's regulatory agency. These agencies cannot do their jobs to their fullest without the participation of civil society and those who doggedly "watch the watchdogs."

## Help Us Help Others.

We look forward to your thoughts and ideas to ensure that the important items under consideration can be incorporated or used to improve the quality and oversight of regulations of nursing homes - in the US, Canada and throughout the globe. For more information about Gray Panthers, please visit our site at [www.graypanthersnyc.org](http://www.graypanthersnyc.org)

### Session Highlights

**Anne Margriet Pot** *Senior Health Advisor, World Health Organization (WHO).* <http://www.who.int/ageing/long-term-care/en/>

Oversees the WHO work on the establishment of sustainable and equitable health systems worldwide using a framework to foster healthy aging to enable older persons to age healthily worldwide..

Ms. Pot focused on the intersection of healthy aging and long-term care, with a specific lens viewing the capacity and ability of individuals over the lifecourse. As expected, this capacity tends to decline over time. Ms. Pot asserts that this should not strip individuals of their fundamental rights, their agency, or the quality of care. Her presentation also touched on development of long term care systems in Sub Saharan Africa. <http://www.who.int/ageing/publications/ltc-series-subsaharan-africa/en/>

**Tina Kim** *Deputy Comptroller for State Accountability at Office of the New York State Comptroller* <https://www.osc.state.ny.us/audits/allaudits/093016/15s26.pdf>

The Office of the State Comptroller ensures that government is doing what it is supposed to be doing. The effectiveness of regulations of nursing homes in New York State has become an important concern for this office. While the Comptroller's office audits government expenditures, performance audits, such as recent reviews of the effectiveness of penalties and fines for serious violation of nursing home facilities, is also of paramount importance. .

As reflected in the statement of the Comptroller's Office (see link below) Tina Kim reflected on the need for independent advocates to bring problems to the attention of regulators and policy makers. Particularly in instances where vulnerable populations are subject to improper behavior, the voice of educated and concerned advocates may educate regulators to audit, conduct oversight activities, review and/or adjust government and institutional systems. In the U.S., regulation of nursing home is complex, overseen by the US Center for Medicare/Medicaid Services as well as state and local governmental refinements. Measurement tools reflect the direction originally set by underlying legislation and regulation. She further discussed the critical role of government auditors and other types of advocacy organizations to assess if these programs are functioning properly. Unfortunately, Kim mentioned, serious issues often arise over how well oversight entities are carrying out their responsibilities.

<http://www.graypanthersnyc.org/archive/accomplishments/oewga---who-is-watching/un-speech-722.pdf>

**Linda Garcia** *International Longevity Centre (ILC) of Canada; and Founding Director LIFE Research Institute - University of Ottawa* <https://health.uottawa.ca/life-research-institute/>

Focused on the importance of addressing the quality of life concerns of nursing home residents, Ms. Garcia sees regulation and oversight as more about giving people options in long term care facilities. Quality of life is maximized by choice and providing as much autonomy as possible.

Linda Garcia considered the complicated notion of balancing regulation with personal autonomy. She noted that it is time to seriously contemplate smarter, rather than additional, regulation. She suggests making regulations more meaningful, updated to today's values, and culturally sensitive. Garcia made a clear push to consider individual autonomy in all decisions, and how this should be fundamental in all regulatory processes, noting that this is especially important in the developing world where these countries are beginning to see a demographic shift with regard to persons aging longer.

[http://www.graypanthersnyc.org/archive/accomplishments/oewga---who-is-watching/garcia\\_2018.pdf](http://www.graypanthersnyc.org/archive/accomplishments/oewga---who-is-watching/garcia_2018.pdf)

**Bethany Brown** *Human Rights Watch, Researcher, Health and Human Rights Division, focused on the rights of older persons.*

A recent and extensive report from Human Rights watch focused on the extent of chemical restraints in nursing homes. Watchdog for human rights, HRW now also has a focus on the rights of older persons. Bethany's presentation made clear why oversight of regulators is essential.

<https://www.hrw.org/news/2018/02/05/us-nursing-homes-misuse-drugs-control-residents>

Ms. Brown provided sobering examples regarding the extent and effect of the inappropriate administration of antipsychotic drugs in Nursing Home facilities. Often administered without informed consent, there are an estimated 179,000 older people given these drugs every week. Over ten weeks, these drugs can nearly double the risk of death. It is important to acknowledge that regulations against these practices exist, but the practicalities for obtaining informed consent from a person with dementia does not. Additionally, fines imposed, if at all, are inadequate to limit the use of chemical restraints in nursing homes.

<https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia> Please note the extensive recommendations found at the end of this report. They will be helpful to advocates and policy makers alike.

**Richard Mollot** *Executive Director, Long Term Care Community Coalition*

Focused exclusively on addressing inadequacies in the care and quality of life options provided to residents of long term care facilities especially nursing homes, LTCCC provides well-researched, pointed and actionable tools for advocacy and reform. <https://nursinghome411.org/>

The LTCCC is a prime example of civil society's effort to "watch the watchdogs" in nursing home regulation. Mr. Mollot identified distinctions between the regulation of assisted living facilities

contrasted to regulation of nursing homes. Assisted living facilities are funded mostly by private payers, while nursing home facilities are paid mostly by Medicare and Medicaid. Federal protections apply to all residents regardless of care payment method. In general, the statutory and regulatory scheme in the U.S. is comprehensive if properly implemented, financed and subject to robust oversight (by government and by the public). For example, the Nursing Home Reform Law, which lays out specific resident rights, is a good foundation for monitoring a quality of life that maximizes choice, dignity and autonomy. Yet, it does not adequately provide resources of oversight, cost control, and enforcement mechanisms. Throughout the country, all too often, nursing home facilities blatantly violate the rights of patients and residents. Consequently, it is imperative that civil society as well as government auditors enhance their efforts to monitor nursing homes and their regulators.

We encourage you to review the attached PowerPoint presentation by Mr. Mollot. It provides a worthwhile overview of government regulation of nursing homes, where it is limited and how advocacy can affect positive change.

<http://graypanthersnyc.org/archive/accomplishments/oewga---who-is-watching/>

LTCCC provides extensive online resources to address issues in regulation of long term care facilities, including nursing homes.

### **The Bottom Line**

Human rights for older persons, especially for those in long term care facilities must be protected. By virtue of their having been sequestered by place and by infirmity, they become invisible. Government oversight bodies as well as civil society advocates must be constantly vigilant to ensure full compliance by nursing home owners, managers and staff as well as to fight for improvements in the quality of life for older persons in nursing homes. This underscores the need for a global Convention to Protect the Human Rights of Older Persons addressing their unique situation. Current treaties and global oversight do not effectively identify and protect the needs of this vulnerable and invisible population. We invite you to be part of this movement to create positive change.

### **Contact Us**

Should you have questions, edits, or concerns, please contact us at 917 535 0457 [www.graypanthersnyc.org](http://www.graypanthersnyc.org) or [jkupferman@aol.com](mailto:jkupferman@aol.com)