LONG TERM CARE
COMMUNITY COALITION

Advancing Quality, Dignity & Justice

KEEPING THE PROMISE TO AMERICAN SENIORS & FAMILIES

RICHARD J. MOLLOT, JD

EXECUTIVE DIRECTOR

LONG TERM CARE COMMUNITY COALITION

WWW.NURSINGHOME411.ORG

PREPARED FOR THE COMMITTEE ON WAYS & MEANS

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I. Introduction

Good morning, Chairman Neal, Ranking Member Brady, and Members of the Committee. Thank you for inviting me to testify on this important issue.

My name is Richard Mollot. I am the executive director of the Long Term Care Community Coalition (LTCCC). LTCCC is a non-profit, non-partisan organization dedicated to improving care and quality of life for residents in nursing homes, assisted living, and other residential care settings. We conduct substantive research on long-term care policies and the extent to which essential standards of care are realized in the lives of residents, who are typically elderly and frail. In addition to conducting systemic analysis and advocacy, we educate and engage residents, families, and those who work with them, so that they are aware of their rights and are equipped to overcome the challenges that so many of our seniors face when they need residential care.

Nursing home residents are among our most vulnerable citizens. By definition, they require 24-hour a day monitoring and care. Residents, and their families, literally entrust their lives to the nursing homes in which they live. For these reasons, there are federal and state standards to ensure that residents are protected and receive the care and services they need to attain their highest practicable medical, emotional, and social well-being. Nursing homes that are licensed to participate in the Medicare or Medicaid programs agree to meet or exceed these standards and are paid accordingly. In addition to the legal obligation to meet federal standards (which, importantly, applies to all residents,

no matter who pays for their care), we believe that nursing homes have a moral obligation to ensure that their residents are provided good care and treated humanely.

Importantly, licensure under Medicaid and Medicare is entirely voluntary. Nursing homes that do not wish to meet minimum standards are free to operate as private facilities.

II. The Important Standards That Protect America's Seniors & Families

The federal standards for nursing homes, known as the Requirements for Participation, exist to implement the federal Nursing Home Reform Law, which became law in 1987 in response to numerous reports of horrific conditions in U.S. nursing homes. The Reform Law is a unique piece of legislation in that it explicitly recognizes the individuality of the consumers of nursing home care and the special duty we owe to those who turn to a nursing home for 24-hour a day care. While most laws focus on the actions of the individual or entity to which they apply (for example, environmental laws that establish minimum miles per gallon efficiency for car manufacturers), the standards implementing the Reform Law focus on meeting the needs, desires, and goals of residents as individuals. They recognize that residents are humans, not manufactured products or faceless entities to which services can be perfunctorily delivered. Importantly, they acknowledge the fact that people do not forfeit their rights as citizens when they enter a nursing home.

These standards are robust, in that they touch on a range of areas that are important to the well-being of every human being, from access to care that meets professional standards to freedom from unnecessary drugs to the right to make choices about one's schedule. At the same time, the standards provide ample flexibility for providers, so that care and services can be tailored to be appropriate for the individual. To that end, nursing homes are required to review the needs of each individual before accepting him or her into a facility and, when they do accept someone, they are explicitly promising that they can provide the professional care and services – including sufficient numbers of competently trained staff – to meet that individual's needs.

Over the decades, these standards have made a positive difference in the lives of millions of Americans. Most nursing homes look better and smell better than they did 30 years ago. The use of physical restraints, once common, is now rare. The basic humanity and rights of older adults and individuals with disabilities, including dementia, are much better recognized now than they were when the Reform Law passed. At the same time, the federal standards are sufficiently flexible to accommodate our society's changing perceptions of aging and disability over the years.

Unfortunately, the growing sophistication and corporatization of the nursing home industry, coupled with the emergence of powerful industry lobbyists in Washington, state capitols, and even academia, have essentially overrun the enforcement system. The Centers for Medicare and Medicaid Services (CMS), which oversees all licensed nursing home care in this country, now openly refers to nursing homes (rather than residents and families) as their "customers." State and federal enforcement, never robust, have weakened to such a profound extent that even basic safety and dignity are, too often, out of reach. Our analyses of federal data corroborate multiple GAO, OIG, academic, and news media reports that today, as in the 1980s, we are once again facing a serious national crisis in nursing home care.

III. Disconnect Between Standards & Reality for Residents & Families

As noted above, though current standards are strong, the persistent lack of enforcement of those standards by the states and CMS has resulted in a situation where a sophisticated, profit-driven industry essentially operates as its owners see fit. Some nursing homes honor their promises to residents and families but many do not. In the absence of effective enforcement, there is little to stop nursing home companies from maximizing profits at the expense of resident care.

There is, sadly, an ever-growing body of evidence to support this assertion:

- **Abuse, neglect, even crimes against residents, are longstanding and pervasive problems**. Serious abuse and neglect are persistent, yet entirely avoidable, problems in communities in every state of the country. A 2003 report noted that "vulnerable individuals in these [nursing home and assisted living] settings are at much higher risk for abuse and neglect than older persons who live at home…."[1,2] This assessment remains painfully true today. A recent U.S. HHS Office of the Inspector General (OIG) report found that one in five high-risk hospital emergency room Medicare claims were the result of potential abuse or neglect of nursing home residents. According to the OIG, nursing homes failed to report an estimated 6,608 potential abuse and neglect incidents to the state survey agencies as required by law in 2016.[3] A recent Government Accountability Office (GAO) report found that the number of abuse deficiencies cited in nursing homes more than doubled between 2013 and 2017 (430 and 875, respectively).[4]
- **Chronic violations of health requirements**. Over 40% of U.S. nursing homes have chronic deficiencies – repeated violations of the same regulatory requirement three or more times in the three years' of inspection results published on Nursing Home Compare.[5] In fact, violations of minimum care standards are so common and widespread that the average U.S. nursing home has eight substantiated violations of minimum health standards per year.[6] Nevertheless, less than half of all nursing homes have received any federal fine whatsoever in the last three years and, of those, the average amount is approximately $1,600.[7] For nursing

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[1] Hawes, Catherine, *Elder Abuse in Residential Long-Term Care Settings: What Is Known and What Information Is Needed?*, National Research Council (US) Panel to Review Risk and Prevalence of Elder Abuse and Neglect, National Academies Press (US); 2003. Accessed at https://www.ncbi.nlm.nih.gov/books/NBK98786/.

[2] See, Mollot, Richard, Valanejad, Dara, and Whang, Sean, *Addressing Abuse, Neglect, and Suspicion of Crime Against Nursing Home Residents: Policy Considerations & Promising Practices* (March 2019). Available at https://nursinghome411.org/ltccc-report-abuse-neglect-crime/. *See*, also, Ellis, Blake and Hicken, Melanie, *Sick, Dying, and Raped in America's Nursing Homes* (February 2017). Available at https://www.cnn.com/interactive/2017/02/health/nursing-home-sex-abuse-investigation/.

[3] Office of Inspector General (OIG), *Incidents of potential abuse and neglect at skilled nursing facilities were not always reported and investigated.* HHS Brief A-01-16-00509 (June 2019). Available at https://oig.hhs.gov/oas/reports/region1/11600509.asp.

[4] Government Accountability Office (GAO). *Improved Oversight Needed to Better Protect Residents from Abuse.* GAO-19-433, (July 2019). Available at https://www.gao.gov/assets/700/699721.pdf.

[5] Mollot, Richard, *Chronic Deficiencies in Care: The Persistence of Recurring Failures to Meet Minimum Safety & Dignity Standards in U.S. Nursing Homes* (2017). Available at https://nursinghome411.org/wp-content/uploads/2017/02/LTCCC-Report-Nursing-Homes-Chronic-Deficiencies-2017.pdf.

[6] Nursing Home Compare data set "Provider Info" downloaded 11/11/19. https://data.medicare.gov/Nursing-Home-Compare/Provider-Info/4pq5-n9py.

[7] *Id*.

homes looking to maximize profits by reducing costs on staffing or services, this is, relatively, a minor expense.

- **Short-term rehab residents at risk**. Many seniors and families are aware of the nursing home industry's poor reputation, but think that going for short-term rehab makes them safe. That is, sadly, untrue. A 2014 OIG study, *Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries*,[8] found that **an astonishing one-third of people who went to a nursing home for short-term care were harmed** within an average of 15.5 days, and that **almost 60% of that harm was preventable and likely attributable to poor care**. This is particularly striking because Medicare reimbursement rates are extremely high. The Medicare Payment Advisory Commission (MedPAC) has reported that nursing homes are overpaid by the Medicare program and have enjoyed margins exceeding 10% for more than 15 consecutive years.[9] Why can't nursing homes take care of these highly profitable patients? What are the implications for our elderly residents, particularly the majority of residents who have dementia?
- **Inadequate access to humane dementia care**. More than 50 percent of residents in assisted living and nursing homes have some form of dementia or cognitive impairment, and 67% of dementia-related deaths occur in nursing homes. Nursing home and assisted living facility safety is of the utmost importance to those living with this disease and their families. Yet far too many facilities fail to anticipate the needs of individuals with dementia or equip their staff with the knowledge and skills necessary to provide comfort and care to residents who are experiencing common behavioral and psychological symptoms of the disease. In what other industry would it be acceptable to be unable to meet the needs of the majority of one's customers?
- **Thousands of elderly residents are chemically restrained with dangerous antipsychotics every day**. The inappropriate antipsychotic drugging of nursing home residents, particularly those with dementia, is a universally recognized, national problem. Despite the Food and Drug Administration's 'black box' warnings against using antipsychotics on elderly patients, they are frequently used to treat the so-called behavioral and psychological symptoms of dementia.

  These and other psychotropic drugs are too often used as a form of chemical restraint, sedating residents so that not only their behaviors but also the underlying causes for those behaviors do not have to be addressed by staff. In addition to destroying social and emotional well-being, these drugs greatly increase risks of stroke, heart attack, diabetes, Parkinsonism, and falls. They are *not* clinically indicated for dementia-related psychosis. They *are* associated with a significant increase in death when given to elderly people with dementia.

  Though modest progress has been made in reducing inappropriate antipsychotic drugging since the OIG Inspector General sounded the alarm about widespread misuse in 2011,[10] the most recent data reported by CMS indicate that about 20% of nursing home residents,

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[8] Available at https://oig.hhs.gov/oei/reports/oei-06-11-00370.asp. Six percent of those who were harmed died, and more than half were rehospitalized.

[9] See http://www.medpac.gov.

[10] Levinson, Daniel R., Inspector General, Department of Health and Human Services, *Overmedication of Nursing Home Patients Troubling* (May 2011). Available at https://oig.hhs.gov/newsroom/testimony-and-speeches/levinson_051011.asp.

approximately 260,000 individuals, are still receiving these drugs today. [11] This drugging is, in fact, so extensive and egregious that it puts the United States in violation of both federal requirements as well as international conventions and covenants on torture and cruel, inhuman, or degrading treatment or punishment.[12]

As noted in the Human Rights Watch report, *"They Want Docile": How Nursing Homes in the United States Overmedicate People with Dementia*,

> In an average week, nursing facilities in the United States administer antipsychotic drugs to over 179,000 people who do not have diagnoses for which the drugs are approved. **The drugs are often given without free and informed consent**, which requires a decision based on a discussion of the purpose, risks, benefits, and alternatives to the medical intervention as well as the absence of pressure or coercion in making the decision. Most of these individuals—like most people in nursing homes—have Alzheimer's disease or another form of dementia. According to US Government Accountability Office (GAO) analysis, facilities often use the drugs to control common symptoms of the disease.
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> **The drugs' sedative effect, rather than any anticipated medical benefit, too often drives the high prevalence of use in people with dementia**. Antipsychotic drugs alter consciousness and can adversely affect an individual's ability to interact with others. They can also **make it easier for understaffed facilities, with direct care workers inadequately trained in dementia care, to manage the people who live there. In many facilities, inadequate staff numbers and training make it nearly impossible to take an individualized, comprehensive approach to care**. Many nursing facilities have staffing levels well below what experts consider the minimum needed to provide appropriate care.[13] [Emphases added.]

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[11] The most recent non-risk-adjusted antipsychotic drugging data made publicly available by CMS are from 2018Q3. Since that time, CMS has failed to respond to FOIA requests for these data, though it is widely acknowledged that the risk-adjusted data do not address growing concerns that nursing homes are giving elderly residents diagnoses of schizophrenia (one of the conditions that CMS considers when risk-adjusting the drugging rates for potentially appropriate uses) in order to use these drugs with impunity. Importantly, the risk-adjusted data that CMS does release have indicated that drugging rates have leveled off and may actually be increasing. In addition, it is important to note that these rates do not include the numbers of residents who are administered other inappropriate psychotropic drugs as a form of chemical restraint.

[12] *Protecting Nursing Home Residents From Chemical Restraints: Action is Needed to Reduce & Eliminate Widespread Inappropriate Antipsychotic Drugging*, Submission to the United Nations Human Rights Review of the United States, LTCCC (April 2015). Available at http://nursinghome411.org/ltccc-submission-to-the-united-nations-human-rights-review-of-the-united-states/. *See*, also, *Mid-Term Report: The Inappropriate Use of Antipsychotic Drugs Among Nursing Home Residents Continues to be Widespread and Immediate Action is Still Needed to Protect Residents from Chemical Restraints*, Submission to the United Nations Universal Periodic Review of
United States of America, Second Cycle, Twenty Second Session of the UPR Human Rights Council, LTCCC (April 2018). Available at https://nursinghome411.org/ltccc-mid-term-report-to-united-nations-u-s-nursing-home-antipsychotic-drugging/.

[13] The full report is available at https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia. As the Human Rights Watch notes, "This report is especially relevant at this time

- **Hundreds of thousands die every year from infections**. The failure to take often basic steps to prevent and control infections is an appalling problem in our nation's nursing homes. According to the CDC, a shocking "1 to 3 million serious infections occur every year in these [LTC] facilities. … Infections are a major cause of hospitalization and death; as many as 380,000 people die of the infections in LTCFs every year."[14]

  Sadly, under the Trump Administration, CMS has proposed reducing – rather than bolstering – infection control protections for nursing homes, as part of its effort to reduce so-called burdens for the nursing home industry, which (as noted earlier) it publicly refers to as its "customers."[15]

IV. These Are Not Abstract Problems

Avoidable pain, degrading conditions, and substandard care are a part of hundreds of thousands of nursing home residents' lives every day. This now includes Holocaust survivors, veterans who have fought for our country, our mothers and our fathers. Too frequently, we hear from people who saw their loved ones suffer and, sometimes worse, the stories of the 25% of residents who do not have a regular visitor, and who rely on their state and country to protect them.

- **Abject neglect**. A family member reported to us that her mother had symptoms of a heart attack. Though the nursing home said they would respond immediately, her mother was not seen by a doctor for two days. Her mother died.
- **Trapped in a nursing home**. We recently spoke to a senior citizen who wound up in a nursing home after a stroke, and is struggling to get the therapy services she needs to go home. "I got sick nine years ago and the government put me in prison, here, and now I cannot get out." Can you imagine living somewhere for nine years and feeling like you are in prison and that it's because you were sick?
- **Maggot infestation**. Inadequate housekeeping and maintenance resulted in a maggot infestation on resident's scrotum. The state survey agency identified this as "no harm."[16]
- **Living – and dying – in pain**. Basic palliative care (freedom from pain) and hospice care (the chance to die in comfort with dignity) are increasingly out of reach for too many of our seniors because their facilities put profit first. A hospital representative informed us that he did not want to send patients to a local nursing home because the administrator of the nursing home had told him "I don't get paid to allow residents to die with dignity."
- **Rose's story: living with dementia**. Rose is a woman in her 80s. When she entered the nursing home near her family, she was in the early stages of dementia but was highly

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because the US is aging rapidly. Most of the people in the nursing facilities Human Rights Watch visited are over the age of 65. Older people now account for one in seven Americans, almost 50 million people. The number of older Americans is expected to double by 2060. The number of Americans with Alzheimer's disease, the most common form of dementia, is expected to increase from 5 million today to 15 million in 2050. The system of long-term care services and supports will have to meet the needs—and respect the rights—of this growing population in coming years."

[14] https://www.cdc.gov/longtermcare/index.html. Note: this includes both nursing homes and assisted living.

[15] For the proposed rule, *see* Requirements for Long-Term Care Facilities: Regulatory Provisions to Promote Program Efficiency and Transparency, CMS-3347-P, available at https://www.regulations.gov/docket?D=CMS-2019-0105.

[16] Statement of Deficiencies for Alden Town Manor Rehab & HCC, CMS (Oct. 31, 2017), https://www.medicare.gov/nursinghomecompare/InspectionReportDetail.aspx?ID=145736&SURVEYDATE=10/31/2017&INSPTYPE=CMPL&profTab=1&state=IL&lat=0&lng=0&name=ALDEN%2520TOWN%2520MANOR%2520REHAB%2520%2526%2520HCC&Distn=0.0.

functional and interested in the world around her. Before she went to the nursing home this might indicate that Rose is a social person, but in the facility she was identified as a "wanderer." Rather than being assisted in acclimating to her new environment in an appropriate way, Rose was given antipsychotic drugs to stop her wandering. She was chemically restrained.

While being given these drugs Rose rapidly declined in health. Her granddaughter thought that this was the result of increasing dementia, and did not even know that her grandmother was being given powerful antipsychotics until she requested that the home conduct a medical evaluation so that they could move Rose to another facility.

Since she left that nursing home, Rose's granddaughter has helped to ensure that her grandmother was taken off the antipsychotics. Though she still has dementia, Rose has regained significant mental functioning and quality of life. The painful bed sores that she acquired while on the drugs have been treated. Unfortunately, she now suffers from permanent movement disorders, a problem associated with antipsychotic drugging, and can no longer walk on her own. Nobody will ever have to worry about Rose "wandering" again.

V. Money is *NOT* the Problem

Nursing homes are paid to provide a professional level of care and services via a system that financially accounts for the varying needs of residents, geographical differences, etc…. Nevertheless, and despite a growing for-profit sector of the industry – the nursing home industry and its multi-million dollar lobby associations have claimed for decades that they don't receive sufficient money to provide better care and life with dignity.

Of course, LTCCC supports funding for sufficient resident services and staffing (including payment of decent wages). However, we believe that **threatening the well-being of vulnerable residents and essentially holding them hostage to demands for more money is nothing short of reprehensible**.

In fact…

- **There is virtually no accountability for how money received to provide care is actually spent by nursing homes**. For example, residents are required to be served palatable, nutritional food. Yet inappropriate and sometimes dangerous dining services are a widespread problem, and too many nursing homes spend just a few dollars a day per resident on food.[17]
- **There is no limit on the amount nursing homes spend on administrative expenses**. A nursing home administrator can make $100,000 per year or over a million. There is nothing to stop a nursing home from paying exorbitant salaries and benefits to senior administrative staff and then claim that it is "losing money."
- **There is no limit on self-dealing**. As *The New York Times* uncovered last year, "Care Suffers as More Nursing Homes Feed Money Into Corporate Webs."[18] Too many nursing homes are

[17] Lundstrom, Marjie, "Bugs, Mold and Unwashed Hands: Rampant Safety Violations in Nursing Home Kitchens Endanger Residents," *FairWarning* (October2019). Available at https://www.fairwarning.org/2019/10/safety-violations-in-nursing-home/.

[18] Rau, Jordan (January 2018). Available at https://www.nytimes.com/2018/01/02/business/nursing-homes-care-corporate.html.

contracting with companies that they own for everything from basic services to renting the property on which the nursing home itself sits. They can pay themselves any amount that they like, and then claim that they have "razor-thin margins" or are losing money.

- **The nursing home industry has had double digit Medicare profits for the past 17+ years**. As noted earlier, MedPAC, which advises Congress on Medicare, called for reducing Medicare payments to U.S. nursing homes by $2 billion this year due to the high profit margins. According to MedPAC's principal policy analyst, "[f]or efficient providers, those with relatively low cost and high quality, the average Medicare margin was 18%, further evidence that Medicare overpays for SNF [skilled nursing facility] care."
- **The nursing home industry (especially the for-profit sector) is booming**. For-profit providers are buying up nursing homes nationwide. Would companies and investment trusts be buying nursing homes if they were truly money losers? Recent national reports have boasted of one chain's nursing homes more than doubling in value and another company's earnings growing by close to 20% since last year.[19]
- **The nursing home industry is gearing up to save millions of dollars under the new federal payment system**. Due at least in part to excessive gaming of the existing Medicare reimbursement system, CMS launched a new payment system last month which the nursing home industry is already leveraging to maximize profits and reduce costs. Again, the lack of accountability for providing decent care and humane conditions allows nursing home to chase profits by cutting staff and services to residents with relatively unbridled impunity.[20]

VI. Recommendations

- **Enforcement of minimum standards is needed**. We must address the disconnect between the promise of the Nursing Home Reform Law and reality: neither the state agencies nor CMS are fulfilling their mission to protect residents and the integrity of the Medicare and Medicaid programs.
- **Hold the line** against current efforts to undermine regulatory minimum standards and reduce the already low frequency of nursing home inspections. Residents' lives – and families' peace of mind – depend on it.
- **Codify federal minimum staffing standards**. The widespread failure to provide sufficient care staff – universally recognized for decades – is a national disgrace. We have known since 2001 that at least 4.1 hours of care staff per resident per day is needed to prevent poor clinical outcomes.
- **Establish a medical loss ratio for nursing homes**. American families and taxpayers have a right to know that a reasonable percent of the public funds that nursing homes receive to provide care to vulnerable seniors is actually going towards that care, and not being siphoned off into uncapped profits, unrestricted administrative expenses, or – as frequently happens – unlimited, unaudited related-party transactions.

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[19] See, for example, Brown, Danielle, "Ensign execs tout 'extraordinary' third quarter results," *McKnight's Long-Term Care News* (October 2019). Available at https://www.mcknights.com/news/ensign-execs-tout-extraordinary-third-quarter-results/.

[20] See, for example, Spanko, Alex, "PDPM Therapy Changes, Staff Reductions to Bring Genesis $30M in Annual Savings," Skilled Nursing News (November 2019). Available at https://skillednursingnews.com/2019/11/therapy-changes-staff-reductions-to-bring-30m-in-savings-per-year-for-genesis/.

- **Alternative options to nursing home must be safe, accessible, and affordable**. Seniors and families want and deserve options to nursing homes that provide safety in a more home-like setting. While most states are rightfully opening up assisted living to Medicaid beneficiaries, the utter lack of federal standards in this sector has, unsurprisingly, led to increasing reports of rampant abuse and neglect. Our seniors and their families deserve better.[21]

Thank you for your consideration of our testimony and the issues raised herein.

Richard J. Mollot, Executive Director
Long Term Care Community Coalition
One Penn Plaza, Suite 6252
New York, NY 10119
Phone: 212-385-0355 Email: info@LTCCC.org
www.nursinghome411.org

[21] See, for examples, Teegardin, Carrie and Schrade, Brad, writing in *The Atlanta Journal-Constitution*'s investigation detailing abuse and neglect across Georgia's senior care industry (articles include "Suffering behind the façade," Georgia families in the dark about risks," "Son searches for answers in mother's alleged assault," and "Prosecutors not alerted to potential crime") (September – October 2019). Available at https://www.ajc.com/senior-care-quality-report/.