

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

MEMO IN SUPPORT:

Two Bills to Ensure Informed Consent for The Use of Psychotropic Medication in Nursing Homes and Adult Care Facilities

TITLE OF BILL I: An act to amend the public health law, in relation to the use of psychotropic medications in nursing homes and adult care facilities. ([A01033](#))

TITLE OF BILL II: Supports essential rights of residents of adult care facilities, including right to be informed about one's condition, treatment and medications. ([A01084](#)/[S00874](#))

POSITION: The Long Term Care Community Coalition (LTCCC) strongly supports these bills, in recognition of the urgent need to reduce the inappropriate, off-label use of powerful and dangerous antipsychotic drugs in nursing homes and other adult care settings.

STATEMENT OF THE PROBLEM: Inappropriate and dangerous antipsychotic drug use is a widespread problem in nursing homes and other adult care facilities. The US Food & Drug Administration has issued its highest ("black box") warning against using antipsychotics on elderly patients with dementia, due to their increased risk of heart attack, stroke, Parkinsonism and, even, death. Nevertheless, too frequently, they are used as a form of chemical restraint without residents or families receiving appropriate information or providing informed consent.

The federal government, state government, nursing home industry, and consumers have all recognized the seriousness of the current problem and the need for corrective actions:

- **According to a recent [Human Rights Watch](#) report:**

Every week, more than 179,000 people in nursing homes in the United States are given antipsychotic drugs even though they have not been diagnosed with any condition for which their use is approved. Often, facilities administer the drugs without making any effort to seek informed consent. Many nursing homes use these drugs not to treat a specific medical condition—such as psychosis or a neurological disorder—but because of their sedative effect. Antipsychotic drugs make nursing home residents easier to control by pacifying and sedating them.

A large proportion of people in nursing homes in the US have dementia, a brain disease that profoundly affects memory, communication, and other cognitive functions. In nursing homes without adequate staff numbers or without nursing staff adequately trained in dementia care, the facility may turn to antipsychotic drugs to sedate people who have difficulty

communicating their needs and who act in a “disruptive” way from the facility’s perspective. The underlying cause of a person’s distress is often never addressed.

- In 2011, U.S. Inspector General Levinson stated, “Too many [nursing homes] fail to comply with federal regulations designed to prevent overmedication, giving nursing home patients antipsychotic drugs in ways that violate federal standards for unnecessary drug use.” ***The Inspector General concluded, “Government, taxpayers, nursing home residents, as well as their families and caregivers should be outraged – and seek solutions.”***
- In March 2012, the federal government began a campaign to address this problem. States were charged with an initial, “modest” goal of reducing their drugging by 15% by the end of that year. ***NY only achieved about half of the national goal for reducing antipsychotics.***
- ***Today, close to one in five nursing home residents in NY State are still being given antipsychotic drugs.*** Less than two percent of the population will ever be diagnosed with a condition recognized by CMS in its risk-adjustment for potentially appropriate use.
- ***Antipsychotics do not help address the underlying causes of so-called “Behavioral and Psychological Symptoms of Dementia,”*** such as agitation. They merely mask the resident’s problems, which may be due to pain, boredom, fear or even discomfort from an underlying infection. The standard of care, which has been federally required since the early 1990s, is to provide residents with dementia care that employs non-pharmacological interventions. Antipsychotics are not indicated for “dementia-related psychosis.”
- ***Inappropriate antipsychotic drugging is a serious problem for assisted living residents and families.*** A recent study indicated that the majority of assisted living residents have dementia and an astounding 37% of them are administered antipsychotic drugs.

WHY THESE BILLS ARE NEEDED: Too often, these drugs are given to residents without their - or their family members' - consent. Both of these bills would strengthen informed consent requirements to ensure that facility residents are not given powerful and dangerous drugs without being properly informed of relevant information, including the risks and benefits.

Nursing home residents (or, for resident who lack capacity, their families and representatives) have long had the right under federal law to be fully informed in advance about care and treatment and of any changes in that care or treatment that may affect the resident’s well-being, to participate in planning care and treatment or changes in care and treatment and to accept or decline such treatment. **These bills would help make these rights a reality for New York’s nursing home residents and families.**

FOR FURTHER INFORMATION:

Please visit LTCCC’s website, www.nursinghome411.org, for information and resources on antipsychotic drugging, the latest federal data on nursing home antipsychotic drugging rates, and our Dementia Care Advocacy Toolkit for consumers and caregivers.