To: Chairwoman Davis, and Members, Children and Seniors Committee
From: Rachel Monger, Vice President of Government Affairs
Date: March 20, 2018

Testimony in Opposition to House Bill 2704

Thank you, Madame Chair and Members of the Committee. I am Rachel Monger, Vice President of Government Affairs for LeadingAge Kansas, the state association for faith based and other not-for-profit aging services. We have 155 members across Kansas, which include not-for-profit nursing homes, retirement communities, hospital long-term care units, assisted living, homes plus, housing, low-income housing, home health agencies, home and community based service programs, PACE and Meals on Wheels. Our members serve more than 25,000 elders each day.

We are speaking to the Committee today in opposition to House Bill 2704. The requirements set out in the bill are ineffective, unnecessary, and will ultimately cause more harm to elders with dementia that are in need of care.

HB 2704 is Ineffective in Addressing Systemic Issues Behind Antipsychotic Overuse

Kansas has made a significant reduction in antipsychotic use since the federal reduction began in 2011. However, our statewide reduction has been slower than other states, and has stalled out in the last two years. It is upsetting and frustrating to everyone involved in the situation, and that includes nursing home providers. We know why the state has lost ground on antipsychotic reduction, and we have the data points to show it. The real question is whether policy makers are willing to pursue the solutions required to truly address the problem.

Attached to our testimony is a graph detailing average antipsychotic usage rates in nursing homes from 2011 through the third quarter of 2017. There are data points for the state average, national average, state for profit average, and state not for profit average. (We are happy to note that not for profits constitute half of the long term care providers in Kansas, and they continue to beat most of the nation on antipsychotic use and reduction rates.)

As the graph demonstrates, we were slowly, but steadily reducing antipsychotic use across the state. However, that trend came to a sudden stop, and starting January 1, 2016 the antipsychotic rate in Kansas spiked. Kansas has continued to lose ground on antipsychotic reduction over the last two years. When looking at what has occurred in the state long term care system since 2016, the reason for the reversal is clear.

A brief summary of what nursing home providers have endured since the start of 2016:

- Two rounds of Medicaid funding cuts. Nursing homes received a cut of 4.47% in 2016, which was restored in 2017, but immediately followed by a 3.65% cut to rates in the current fiscal year.
- A broken Medicaid eligibility system that caused a severe backlog, and stole tens of millions from providers.
- A crippling 9,000% increase in fines due to a broken survey system that has run amok.
- A complete re-vamp and massive expansion of federal nursing home regulations.

Nursing homes are still experiencing these issues two years later, and these factors continue to be the drivers behind antipsychotic use. Dementia care is a more intensive and specialized kind of care, and requires a lot more resources than other forms of care in the nursing home. This is especially true when medications are not being used to relieve behavioral symptoms. The resources a nursing home needs boils down to two things:

1. Money, in the form of adequate Medicaid funding
2. People, in the form of an abundant, stable and well-trained workforce

Nursing homes today have neither.

Instead of more threats of legislation, penalties and litigation, we need open discussion, careful thought and collaborative care models. We need investments and repairs for a long term care system that our state has allowed to crumble over the course of many years. Only then will Kansas make true and lasting progress on the reduction of off-label antipsychotic use for the treatment of dementia.

HB 2704 is Harmful to Elders with Dementia Who Are In Need of Care

1. Shrinking Access to Care

In the last few years, we have seen the access to care for persons with dementia contract rapidly. Door after door is being closed to dementia sufferers that have even a hint of "problem behaviors." High quality providers are screening out more and more prospective residents due to a lack of resources to care for them, and terror over potential survey penalties and lawsuits if something goes wrong.

Many Children and Seniors Committee members have spoken with senior care providers in their districts, and are aware of the explosion of high level citations and enforcement penalties that have been levied against nursing homes in the last two years. What many of the Committee members may not know is that a large number of the increased citations have centered around residents with dementia. In particular, incidents of physical violence, verbal abuse, inappropriate touching, and sexual behaviors that government regulators decided put all of the other residents in the facility at risk. As workforce and funding for senior care has shrunk, so has the ability of high quality providers to care for people with challenging dementia symptoms. As regulations, penalties and potential litigation have increased, the range of people being admitted to high quality nursing homes have shrunk.

If passed, House Bill 2704 would be the broadest-based, and most restrictive informed consent law for antipsychotics in the nation. It would be one thing to impose these kinds of requirements on a healthy,

well-functioning long term care system. But long term care in Kansas is hanging on by a thread. HB 2074 does nothing to address the systemic issues behind antipsychotic use. It does increase requirements, penalties and potential litigation for providers already short of resources, and scared to take a risk and open their doors to residents who may need more complex dementia care. At this juncture in Kansas, any small effect HB 2704 would have in reducing antipsychotics would be far outweighed by the even further loss of available care for seniors with dementia.

2. Expanding Requirements Outside of the Nursing Home

If passed, HB 2704 would be the only informed consent law for antipsychotics that applies to settings other than a nursing home. The legislation achieves this in two ways. First, it specifically references "adult care homes" as defined in K.S.A. 39-923. In Kansas law, an adult care home is *any* type of licensed, residential senior care. This includes nursing homes, assisted livings, homes plus, residential health care facilities, board and care homes and adult day care. As outlined later in our testimony, we believe there are aspects of the bill that would have a particularly negative impact in assisted living and other similar settings.

The second way HB 2704 expands informed consent requirements beyond a nursing home is that it attaches the requirements to adult care home *residents*, not adult care home *settings*. Therefore, informed consent for antipsychotics must be followed wherever the resident goes for health care services, such as a hospital, behavioral health unit, doctor's office, clinic or psychiatrist's office. We generally agree that if special rules are to be put into place around informed consent for antipsychotics, they need to be applicable to the entire continuum of care. However, there is also real danger in legislating health care. The farther reaching the law, the higher risk of unintended consequences and restrictions to needed services

3. Definition of Retaliation

We have extremely serious concerns with the definition of "retaliation" as used in the bill. Paragraph (c)(8) [page 3, lines 21-23] states:

"No person may retaliate against or threaten to retaliate against the resident or a person acting on behalf of the resident for refusing to provide or withdrawing consent."

Our concern is that necessary treatments, and even compliance with state and federal laws, will be interpreted as "retaliation" by resident representatives, and even state surveyors. Residents and their representatives in a nursing home already have the right under state and federal regulation to refuse medical treatment or medication. The home must accommodate those choices to their every ability. However, basic standards of care and safety must be met. There may come a time when every available alternative and approach has been tried, and the only option left is an antipsychotic medication. If consent is still withheld, the home has both a legal right, and a legal obligation, to discharge the resident to a different setting that can meet their needs. The same is true for needed psychiatric evaluations, and transfers to hospitals and geri-psych units when resident actions become harmful to themselves or others.

The definition of "retaliation" is an even bigger concern in assisted living settings. Assisted living facilities are not nursing homes, nor should they be treated as such. They do not have medical directors, they do not staff like nursing homes, and they determine their own criteria for admission and discharge.

Assisted living, and similar providers, are especially at risk with a broad interpretation of retaliation while taking actions that are necessary to their ability to serve and protect residents in accordance with their policies, contracts, and state regulation.

There is no specific and narrow definition of "retaliation" within HB 2704. If providers are handcuffed from taking necessary safety and legal actions due to retaliation concerns, even more doors are going to close to persons with dementia. Especially in less restrictive settings like assisted living.

4. **Residents Without Representatives**

Our final concern with HB 2704 is regarding access to care for residents without a legal representative, and residents with a legal representative that is unavailable and/or uninterested in participating in the resident's health care. A large number of nursing home residents fall into this category, and it is unclear to us how they are to be treated under HB 2704. From our reading of the bill it seems that an antipsychotic may be prescribed in an emergency, ten days may pass, and if the doctor believes a longer term use is needed, it must be reauthorized either every ten days or every 24 hours. This is completely unworkable in every health care setting where the resident is receiving treatment. It will result in a significant number of residents losing access to care they need, and will be a strong disincentive to serve seniors with no representative or a less than responsive one.

HB 2704 is Unnecessary Due to New Federal Regulations on Antipsychotics and Informed Consent

While federal nursing homes regulations previously addressed the problem of unnecessary drugs for nursing homes residents, there was nothing in federal regulation to address the more recent issue of off-label antipsychotic use. There was also no regulation addressing informed consent. Therefore, enforcement of regulations around antipsychotic prescriptions was limited. That will no longer be the case.

1. **Antipsychotic Regulations**

In response to this enforcement need, CMS enacted new regulations specific to antipsychotic medications in nursing homes. The new requirements, which went into effect on November 28, 2017, require that antipsychotics not be given unless clinically indicated. They also require gradual dose reductions for antipsychotics that are properly prescribed, and put hard limits on the use of antipsychotics on an "as needed" basis.

§483.45(c)(3) A psychotropic drug is any drug that affects brain activities associated with mental processes and behavior. These drugs include, but are not limited to, drugs in the following categories: (i) Anti-psychotic; (ii) Anti-depressant; (iii) Anti-anxiety; and (iv) Hypnotic

§483.45(e) Psychotropic Drugs. Based on a comprehensive assessment of a resident, the facility must ensure that—

§483.45(e)(1) Residents who have not used psychotropic drugs are not given these drugs unless the medication is necessary to treat a specific condition as diagnosed and documented in the clinical record;

§483.45(e)(2) Residents who use psychotropic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated, in an effort to discontinue these drugs; §483.45(e)(3) Residents do not receive psychotropic drugs pursuant to a PRN order unless that medication is necessary to treat a diagnosed specific condition that is documented in the clinical record; and

§483.45(e)(4) PRN orders for psychotropic drugs are limited to 14 days. Except as provided in

§483.45(e)(5), if the attending physician or prescribing practitioner believes that it is appropriate for the PRN order to be extended beyond 14 days, he or she should document their rationale in the resident's medical record and indicate the duration for the PRN order. §483.45(e)(5) PRN orders for anti-psychotic drugs are limited to 14 days and cannot be renewed unless the attending physician or prescribing practitioner evaluates the resident for the appropriateness of that medication.

The CMS Appendix PP Guidance to Surveyors states that the intent of this requirement is that:

• each resident's entire drug/medication regimen is managed and monitored to promote or maintain the resident's highest practicable mental, physical, and psychosocial wellbeing;

• the facility implements gradual dose reductions(GDR) and non-pharmacological interventions, unless contraindicated, prior to initiating or instead of continuing psychotropic medication; and

• PRN orders for psychotropic medications are only used when the medication is necessary and PRN use is limited.

2. Informed Consent Requirements

CMS also revised the resident rights section of the nursing home regulations to require a physician or other practitioner to provide informed consent to a resident or resident representative in advance of treatments. As stated in new regulation, the resident has…

§483.10(c)(5) The right to be informed in advance, by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment and treatment alternatives or treatment options and to choose the alternative or option he or she prefers.

The CMS Appendix PP Guidance to Surveyors further states in regard to this regulation that:

The physician or other practitioner or professional must inform the resident or their representative in advance of treatment risks and benefits, options, and alternatives. The information should be communicated at times it would be most useful to them, such as when they are expressing concerns, raising questions, or when a change in treatment is being proposed. The resident or resident representative has the right to choose the option he or she prefers.

We want to further note that in the CMS Appendix PP Guidance to Surveyors, the guidance on antipsychotics use (F Tag 757) instructs nursing home surveyors to look for resident education and consent six separate times when determining whether the home is complying with antipsychotic use requirements. It also specifically references 483.10(c)(5) and the accompanying guidance on informed consent as a special area of focus.

The new federal regulations will not only move the needle on reducing antipsychotic use in nursing homes. They also manage to address the informed consent issue without disrupting the entire health care system for people with dementia, without cutting off access to needed care, and without interfering in the doctor patient relationship. HB 2704 can make no such claim.

Conclusion

While we do not support HB 2704, we are grateful for the attention and opportunity for discussion that the bill has brought forth. We respectfully request that the Committee grant long term care providers an opportunity they have never before been given. That is the opportunity for a forthright, in-depth exploration of the systemic issues in our long term care system that have left us plagued with issues such as the overuse of antipsychotic drugs. Before pushing for new health care legislation and sweeping public policy change, we ask that the Committee allow us to collaborate with all parties to this issue, to conduct an in-depth study of the complex factors surrounding antipsychotic use, and to develop recommendations and concrete action plans to truly tackle inappropriate antipsychotic use.