"Thank you, Madam Chair, and committee members for your time today and for giving me the honor of speaking in front of you in support of HB4841 also known as Theresa's Law, in memory of my mother, Theresa Sella Skrabis.

I am here to talk about a serious and overlooked problem – the abuse and neglect of vulnerable adults living in Adult Foster Care (AFC) and a system that is failing to protect them due to the low standards of Public Act 218.

I have been unfortunate to learn these facts the hard way, after my mother suffered abuse, neglect, and indignity in an AFC facility two years ago.

My mother's time in the facility she resided was short, only one month before she died, but it was long enough to recognize serious problems. Reality was in stark contrast to what we were promised and what the facility claimed on their website.

The staffs' behaviors were inappropriate, negligent, and abusive.

For example, while I was visiting my mother the weekend of her birthday, staff told stories and joked about residents dying on their shift in front of my mom and referred to themself as "the angel of death." My mom was already afraid of dying and this did nothing to ease her fears.

They were unskilled in proper medication administration, for which I could cite numerous examples, but the most serious was the mismanagement of my mother's insulin. While I was there, staff came in and gave my mom her fast-acting NovoLog shot which was prescribed to be given with meals.

After she gave the shot, I asked the staff member when she would bring my mom her dinner? She said, "We don't serve dinner for another hour yet." I told her my mom could not have her shot this early before eating as the insulin is fast acting\*. The staff member apologized and said she didn't know and would make sure it was given with meals going forward.

I could visibly see my mother's glucose levels were rapidly dropping as her eyes became glazed, her face reddened, and she started to drift off. I quickly had her eat the treats I had brought for her birthday to get her levels back up.

Hypoglycemia (low blood glucose levels) has serious short-term and long-term adverse health consequences, which I have provided, and if untreated can rapidly progress to seizures, coma and even death. Short-term dangers include:

- brain bleed
- <u>heart attack</u>
- impairment to a person's cognitive function

We later learned, after reviewing mom's chart, that they had continued to give my mom her insulin shot between 45mins. -1 hour before meals on multiple occasions.

Most egregiously, however, they bullied and intimidated my mom after she had a serious fall out of bed that caused injuries to her ribs.

My mother's fall occurred on a Friday evening. The following day she was in so much pain whenever she moved or breathed, they started her on morphine. At lunchtime, she asked to eat in her room due to her level of pain, but the staff refused her. They said, "We eat lunch and dinner in the dining room here!" and told her if she wanted to eat, she had to go down to the main dining room.

I don't know if you've ever bruised your ribs, but I have and it was extremely painful at my age. I can't imagine how painful this was for my mom at 91. It's also important to know that my mom was the least demanding person I've ever known. She never wanted to inconvenience anybody. So, for her to ask for help, she had to really be in pain.

Despite this, the staff forced my mom to be transported to the main dining room, which was no easy task as my mom was struggling to walk on her own *prior* to the fall. Staff had to pull her out of her recliner and get her into a wheelchair to "transport" her to the dining room.

It is unimaginable to me the physical pain this must have inflicted upon my mother or how the staff's abusive behavior exacerbated her injuries all because they refused to simply bring a meal to an injured 91-year-old as requested.

I spoke to my mom by phone that evening. She was so distressed and angry that they had bullied her. When she told me about the staff forcing her to go to the dining room, she repeated twice, "They made me!" and cried, "I am in so much pain."

When I told her I was going to call the staff to talk to them and have them help her get ready for bed, she said, "Don't you dare call them! I don't want them in here. I don't want them touching me!" Experts warn this is often a sign of physical or emotional abuse.

I said, "Mom, what are you going to do if you have to go to the bathroom?" She said, "I'll go in my pants if I have to and I'll sleep in my chair tonight."

My mom was fighting to hold on to what little dignity she had left, even in her vulnerable and weakened state. She was willing to suffer whatever personal humiliation that may ensue rather than risk being bullied and intimidated again by staff.

My mom rapidly declined and died the following Saturday – one week to the day of the willful act of cruelty by her "*caregivers*".

There were other issues that occurred that I simply cannot talk about because they are just too painful and I am still trying to maintain some of my mother's dignity.

My family and I were sickened, angry, and heartbroken that our mom's last week of life was filled with emotional and physical distress caused by the very people she was paying handsomely to protect and care for her.

I would like to add that during this time, the empathy and dignity shown to our mom by the Hospice workers was night and day compared to that of the facility staff. I believe that is likely due to the disparity in education and training they receive.

After our mom's passing, we wrote numerous letters to the facility but did not receive a response from them – not one word.

We also filed a complaint with LARA.

The investigation resulted in 2 violations of failure to provide safety and protection of a resident and failure to treat resident with dignity and respect.

We were told the facility could not be cited for a violation for mismanaging mom's insulin because adult foster care facilities are not held to the same standards as homes for the aged and nursing homes.

The AFC said they adhere to the Michigan Department of Health and Human Services (MDHHS) policy that non-time critical medications can be given within 1 hour of prescribed time and the investigator accepted this as valid. However, when we confirmed through a FOIA request with MDHHS that NovoLog is a *time critical* medication, the investigator said the AFC could not be held to that standard as it only applies to facilities governed by MDHHS and not those governed by LARA.

This didn't make any sense to us. The same medications have the same adverse impact if not administered correctly regardless of where a person lives.

For the violations that were substantiated, the facility submitted what we believed to be an insubstantial Corrective Action Plan (CAP) which consisted of 2 online residents' rights courses and 1 sensitivity course.

The facility wasn't even cited for a residents' rights violation (although they should have been). The staff member who committed the willful act of cruelty didn't complete both residents' rights courses, and no one took sensitivity training. On top of that, the staff's abuse and negligence weren't even addressed.

We were in disbelief. The system had failed our mother both before and after her passing. Families, Children, and Seniors Committee Page **4** of **11** Theresa's Law Testimony-HB4841 P. Skrabis 9/19/2023 We began researching other cited violations and learned we were not alone. Ours was not an isolated incident. What we found was alarming.

We compiled three years of complaint data from LARA (see corresponding slide for dates). As you can see, alleged and substantiated allegations rose significantly each year. For Adult Large group homes, there was more than a **76%** increase in substantiated violations from year 1 to year 3. These stats represent only the cases we *know* about as abuse is often under reported and under investigated due to:

- Families/residents fear of retaliation
- Families/residents unaware of how to file a complaint
- Staff fears of recrimination
- Residents often are not believed or have died
- Complaints are hard to prove

The National Center on Elder Abuse estimates that only approximately 1 in 24 experiences of elder abuse is reported. And 1 in 6 adults likely suffer some form of abuse. That number is higher for people with cognitive issues as they are often less likely to be believed, and therefore, investigated.

For example, at the facility my mom resided, a family submitted a complaint that a staff member got in their mother's face, who had dementia, slapped her hands, and called her a bitch. (SIR: AL700397750\_2021A0355014)

The facility immediately denied the accusation, saying the employee in question is well liked and respected and has worked there for several years without any issues. The staff member also denied it. However, the family produced a video from a camera they had in their mother's room and sure enough – it happened exactly as they reported.

This is a case in which, were it not for the camera, the abuse would not have been reported or their mother likely would not have been believed.

We also saw a pattern of repeated offenses suggesting that Corrective Action Plans are not an effective deterrent to prevent recurrences.

Following are three examples.

First, in December of 2022 an 82-year-old woman was locked out of her residence in Bath Township. She was found the next day by the snowplow company curled up in the parking lot. She was rushed to the hospital and placed on life support. She died later that day of 'extreme cold exposure.' This licensee had a prior elopement violation, in addition to numerous other violations, and the only course of action was for them to submit a CAP. Had they been fined, perhaps they would have taken the deficiency more seriously and this poor woman would not have died a cruel and painful death. (AH190401909\_2023A1027025) (Prior violation report: SIR: AL190383349\_2021A0577048)

Second, a facility in Kalamazoo was cited for repeated violations of failed fire safety inspections, nonworking fire alarms, and failed evacuation procedures. Each time, they were required to submit a CAP only. (SIR: AL390016015\_2022A0581011)

After these occurrences, they had a false fire alarm in the middle of the night and a resident was dragged and dropped by staff attempting to evacuate residents. She had scrapes and bruises on her feet and legs. When interviewed, staff stated, "Her leg didn't look too twisted." She was taken to the hospital in extreme distress where she died 3 days later. The facility was ordered to provide -- you guessed it -- a CAP.

And third, a facility, also in Kalamazoo, admitted a resident that they assessed as needing close supervision for safety. This resident's assessment plan indicated he was on, "Direct Line of Sight status for his safety." It also stated he needed 1:1 monitoring for eating as he is a choke risk and required a special puree diet. He needed constant monitoring.

This facility was cited for failure to provide safety and protection for this resident according to his needs in the assessment plan and failure to update his assessment plan not once, not twice, not three times, but *FOUR* times. The first 3 times, the facility was required to submit a CAP. On the fourth occurrence, the resident choked to death. Only then was the recommendation made to revoke this facility's license. Perhaps had they been fined the first, second, or even third time this resident might still be alive today. (AL110366290\_2022A0579005)

We have read hundreds of investigation reports and heard stories from families of horrific cases of abuse, neglect, and indignity, such as:

- Residents left in feces crested, urine soaked under garments
- Untreated urinary tract infections; staff failure to recognize symptoms and seek timely medical attention
- Non-existent, incomplete, inaccurate assessment plans
- Residents not showered for weeks
- Verbal, emotional, physical abuse of residents: hit with brooms, electrical cords, punched, etc.
- Sexual assault of residents
- Residents bullied and denied rights
- Residents dropped, injured during improper lift assists
- Medication Errors/Mismanagement with adverse effects, including death:
  - Untimely administration of insulin
  - Staff crushing time released capsules
  - Residents given double dosages of medications (ex: morphine "nonmedical staff confused between ml and mg" – quote from afc)
  - Residents not given medications for weeks

These stories are hard to read, especially when read them through the lens of this happening to your loved one.

As we began exploring AFCs in Michigan more, we recognized that we had a moral obligation to do something. Even though it was too late for our mom, we couldn't bury our heads in the sand and ignore what was happening. And that is why I am here today.

This became the impetus for Theresa's Law (TL). It is a proactive solution which focuses on 3 main deficiencies of PA218:

- Accountability Fines for abuse, failure to protect, violating residents' rights
- Staff education and qualifications
  - Certified Medication Aide for administering medications
  - Non-certified staff courses (CNA and above exempt)
  - Continuing Education (CE) & Yearly competency tests
- Transparency (Disclosure) requirements to empower families to make informed decisions, including AFC designation (not assisted living) and governed by PA218

Note: We were not aware that the facility we chose for our mother was an adult foster care facility as they identified and marketed themselves as an *Assisted Living* facility as do most AFC Families, Children, and Seniors Committee Page 7 of 11 Theresa's Law Testimony-HB4841 P. Skrabis 9/19/2023 facilities for the aged and Homes For the Aged facilities. This is very deceptive and confusing for families if not disclosed. Families in most cases will not know that two types of assisted living facilities exist that apparently have various levels of care they provide and regulations they must follow.

These provisions are based on the top 3 categories of cited violations from the data we obtained from LARA: Resident Protection, Resident Medications, Resident Care. Our state-by-state comparison of assisted living regulations, which I have provided, shows many states already have similar provisions enacted.

Senior care is BIG business and the care provider community has a powerful and influential voice that believes the marketplace should drive quality of care. However, that approach is not working. There also exists many consulting businesses that help facilities maximize their profits, all while earning profits for themselves. But this is more than a business – we are dealing with human lives.

When will the focus shift to fixing the systemic issues that are resulting in poor quality of care and driving direct care workers to leave the profession?

- Lack of accountability
- Lack of education and training of staff and low pay
- Lack of disclosure and transparency to empower families

# Let me tell you a little bit about my mom.

- My mom was a beautiful soul. She was a funny, compassionate, and loving mother, grandmother, and friend.
- She lived out her values of hard work, integrity, and love of family.
- She raised 7 children with my dad on a small farm while holding down a full-time job.
- She was the first to care for ailing family members, often doing the undesirable. She always put others before herself.
- She was a fabulous cook! She lived up to her Italian heritage in the kitchen. Sunday spaghetti dinners & large holiday feasts were the norm for our family. Mom made it all happen without ever letting on how much work it was. She was so selfless!
- She deserved to live out the end of her life with dignity and respect. She deserved so much better than she received from the facility and system that failed her, as do all our seniors.

## **Closing Statement**

This issue impacts us all as we are all aging and have loved ones who are aged. We will all come to the point in our lives where we will need help with our most personal needs that are often sensitive in nature and what happened to my mom and others could very well happen to you and me.

The systemic issues impacting vulnerable adults and seniors in adult foster care will only worsen as baby boomers continue to age and Michiganders find themselves seeking care outside the home and family if nothing is done.

Our time on this earth is short, no matter how many years we live. This is our chance to leave things better than we found them. Don't let my mother's suffering, and that of countless others, be in vain. I urge you to support and prioritize Theresa's Law and leave a legacy that protects and cares for our most vulnerable and gives them a dignified life.

Thank you.

# Addendum

#### \*Dangers of Hypoglycemia

# **Don't wait more than 15 minutes to eat after taking a mealtime insulin** – source: Healthline.com

Rapid-acting insulins, also known as mealtime insulins, were designed to be taken right before you eat to help control your blood sugar more effectively.

As the name suggests, rapid-acting insulin starts to work rapidly in the bloodstream. If you wait too long to eat, your blood sugar can get too low. This puts you at risk for hypoglycemia.

#### The dangers of low blood glucose – source: Johns Hopskins Medicine

At some time, most people with diabetes experience the sweating and shakiness that occurs when blood glucose levels fall below 70 mg/dl — a condition known as hypoglycemia. The average person with type 1 diabetes may experience symptoms of low blood glucose up to two times a week. However, not all are aware that these **symptoms can rapidly progress to seizures, coma and even death if hypoglycemia is severe.** 

#### What causes low blood glucose?

In most cases, low blood glucose results from overtreatment: Either taking too much diabetes medication or **not eating enough food**. Higher doses of medicine than the person actually requires can also lead to hypoglycemia.

**Effects of hypoglycemia in the body** – source: National Institute of Diabetes and Digestive and Kidney Diseases

#### Short-term effects

In severe cases of low blood sugar, short-term complications can

- brain bleed
- <u>heart attack</u>
- impairment to a person's cognitive function

## Long-term effects

Low blood sugar levels have few direct links to critical long-term effects, but they can <u>increase</u> a person's vulnerability to other conditions, such as <u>heart disease</u>.

For example, an <u>older study</u> found that participants with low blood sugar due to <u>type 2 diabetes</u> had an increased risk of developing heart-related conditions and problems in the blood vessels.

Hypoglycemia can also increase the risk of other conditions, including:

- eye disease
- kidney disease
- nerve damage

In severe cases, nerve cells can die from the lack of glucose supply. If there is damage to the nerves controlling the internal organs, the body <u>can</u> enter autonomic neuropathy.

A person with this condition loses the ability to detect low blood sugar levels, and they may not experience symptoms. They might not know that they have low blood sugar, preventing early intervention. This increases the <u>risk</u> of a person developing severe hypoglycemia.

#### Effects on different body systems

Hypoglycemia can affect several body systems in different ways.

- Digestive system
- Endocrine and circulatory systems
- Central nervous system

Consistently low blood sugar levels can be dangerous because a disrupted glucose supply can impair brain function. In severe circumstances, this can cause coma or death.