

Madam Chairwoman Lee, Sponsor Senator Kristin Roers, and members of the Senate Human Services Committee, thank you for allowing me to speak this morning on behalf of SB2145 regarding access to LTC facilities by Designated Caregivers.

My name is Beth Sanford.

I am a Master's-Prepared Registered Nurse, born and raised in North Dakota. I got my start in nursing working in my local LTC facility at age 15.

I was a nurse's aide for seven years before obtaining my BSN and then MSN from UND. My specialty is working with vulnerable populations, including a two-year stint in LTC and a memory care unit as a staff nurse and then nurse manager. For the last five and a half years, I have been employed as an assistant professor at a local university; many of the students I teach are currently CNA or LPN working in Long Term Care. Among the courses and content that I teach are public health, leadership, disaster-preparedness, and ethics. I am also a Doctor of Nursing Practice student specializing in Public Health and Policy. Also, specifically related to this bill, I am a former member of the Reuniting Residents and Families taskforce set up by DHS and a co-founder of the family-led organization, North Dakota Advocacy for Long Term Care.

The Guidelines handed down from the Centers for Medicaid and Medicare Services, Executive Order 2020.22-1 and the VP3 guidance impacts approximately 8,000 residents in Assisted Living, Basic Care, and Skilled Nursing facilities, countless family members and staff across the state—an upward estimate of 100,000 North Dakotans.

While I understand there is no playbook for a pandemic, the unintended consequences of these policies have caused a lot of unnecessary suffering.

I testify before you today not only as a 25Y seasoned healthcare professional but as a daughter of North Dakota whose family has been and continues to be deeply impacted by the current visitation policies.

In December of 2019, our 93Y grandmother moved from assisted living to the combined basic care and skilled nursing side of her facility. The facility's recent renovation had cut off her independent access to activities, chapel, and her life-long friends. Other than the fact that she is legally blind and walks with a walker, she is very healthy. Like every family, the visitor restrictions while residing in LTC began to take their toll on her well-being and quality of life, including her cognition, physical & emotional health. She became unable to operate her phone, isolating her from her only living child and daily visitor, our mother. At one point, she was fearful that our mother was in jail.

Her conversational ability strikingly declined, and she was unable to talk about anything but the weather.

She also complained about increased pain, likely from the hours and hours of sitting isolated alone in her room. Our mother visited her daily at the window. Unfortunately, it was a thick-paned glass that was difficult for my grandmother to hear through in addition to her visual impairment.

In July 2020, after an incident where our family was refused a valid compassionate care visit, we removed my grandmother from the LTC facility. She is now being cared for by our mother and a local woman that we have hired as there is no homecare in our county. Our family has a beautiful end to our story; our grandmother came back to life. At the age of 93, she regained some of her cognitive function, emotional health, mobility, and some. She now sings, dances, laughs, tells jokes, lifts weights, exercises, walks three times per day, attends church and bible study, and participates in all family events. She is truly living her best life.

However, not everyone has the means or ability to bring their loved one home. Many of these families kept contacting us from all over the state, asking for help.

In September of 2020, after seeing several other states enact Designated Caregiver legislation, four resident family members and I looked to our hometown Senator, Dale Patten, for help.

We shared our story and informed him of the devastating unintended consequences of the current policy. Thank you to Senator Patten, Senator Roers, and the Humans Services committee for encouraging revision of the existing Executive Order. The family-led organization, North Dakota Advocacy for Long Term Care, was created at this time as an effort to bring families together. The purpose is to provide a supportive environment, to provide resident and family resources, direct people to the State Ombudsman, inform residents and families of their rights under the 1987 Nursing Home Reform Act, and as a venue to discuss overreach and brainstorm creative solutions to recommend to facilitate visitation. To date, over 16,000 North Dakotans have accessed information from our group and page, a confirmation that we are not the only family with a resident that requires advocacy during COVID overreach. At that time, we began to discuss with Senator Roers the need to follow other states which had enacted Designated Caregiver legislation. That brings us to today.

It is nearly one year since the initial lockdown. We have counties that are green without one positive case in the facility that are still not allowing visitation. There are residents and family members who have not visited in-person or touched their loved ones since March 2020; this is unacceptable. One could question whether this could be considered a violation of the 1987 Federal Nursing Home Reform Act Resident Bill of Rights; therefore, a human rights violation. The September 17, 2020 CMS Visitation Guidelines read:

Failure to facilitate visitation, without adequate reason related to clinical necessity or resident safety, would constitute a potential violation of 42 CFR 483.10(f)(4), and the facility would be subject to citation and enforcement actions.

SB2145 would safely allow residents and designated caregivers to reunite, increasing quality of life and emotional well-being for all parties involved.

This law would release staff from policing resident families and be the sole source of emotional support.

This law would allow facilities to safely begin the process of visitation with the backing of state law without fear of unnecessary repercussions.

The hearts of thousands of North Dakotans: residents, family, friends, and staff are broken. Therefore, this law is imperative not just for the days of COVID but will provide checks and balances to the LTC system going forward so that this never happens again.

Please vote in favor of SB2145; Together, let's make North Dakota a good place to grow old in.

This is my sworn testimony. Thank you for your time and consideration.

Beth Sanford